SAYING NO: WITHHOLDING AND WITHDRAWING MEDICAL TREATMENT FROM NON-PVS PATIENTS

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ABSTRACT

This thesis examines how decisions to withhold or withdraw potentially curative medical treatment from patients (not in a vegetative state) are made and the impact that NHS funding has. The factors taken into account by doctors are identified by examining relevant literature and conducting semi-structured interviews with a number of consultant level doctors from a variety of specialities. The interviews show that decisions to withhold treatment are made differently from decisions to withdraw treatment. It is apparent that decision-making causes much anxiety, particularly when the outcome is death or life of poor quality. Inadequacy of resources has a major influence on some consultants' practices. Existing models, relevant case law and proposals for resource allocation and the withholding and withdrawing of medical treatment from both adult and child patients are critiqued. A decision-making model which can operate ethically in an environment of limited resources is urgently needed. A better approach to decision-making is proposed which is underpinned by respect for autonomy, openness, distributive justice and developing non-discriminatory practice. At the macro resource allocation level, this involves the creation of an independent Strategic Body to identify what conditions the NHS, as a state-funded institution, should treat and advise on which treatments are ethically, medically and legally most acceptable. A decision-making model for the Strategic Body to follow is suggested. At the individual patient level, a decision-making model for doctors to follow is also proposed. It is suggested, as well, that the present situation whereby conflicts move from the bedside to the courts is unhelpful since the expertise of the judiciary is primarily in law not ethics or medicine. Therefore, a tribunal system should be developed which could weight more equally ethical, medical and legal expertise. Additionally, in-house ethics committees should play a greater role than at present.

AUTHOR'S DECLARATION

I declare that the work in this dissertation was carried out in accordance with the Regulations of the University of Bristol. The work is original except where indicated by special reference in the text and no part of the dissertation has been submitted for any other degree.

Any views expressed in the dissertation are those of the author and in no way represent those of the University of Bristol.

The dissertation has not been presented to any other University for examination either in the United Kingdom or overseas.

SIGNED: 

DATE: 6 MARCH 2001

DEDICATION & ACKNOWLEDGEMENTS

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CHAPTER ONE

INTRODUCTION AND METHODOLOGY

Decisions to withhold or withdraw medical treatment can be either planning decisions made for society by a public body or clinical decisions made regarding an individual patient by a physician.[1] Though often these decisions remain secret,[2] occasionally they become the focus of intense media interest as in the case of 'Child B' which highlighted the difficulties faced by patients, families, doctors and healthcare purchasers.[3] Much is written about non-treatment decisions resulting in the death of the patient, particularly regarding those in low awareness states. Less is written about decisions where patient/family preferences are out of step with medical or healthcare purchaser opinion despite Goodman's call for research in this area.[4] The NHS, like any human service organisation, needs to be 'efficient, effective, equitable and humane'.[5] Rationing tends to be covert.[6] The political convention is to deny its existence.[7] Doctors are told to both 'give priority...on the basis of need' and to recognise 'the effects their decisions may have on the resources and choices available to others'.[8] Tension between individual and societal interests results. As Klein et al note, 'there is remarkably little direct evidence about how funding constraints influence medical decisions or about the criteria used when allocating scarce resources to individual patients'.[9]

In broad terms, this thesis sets out to examine the process of decision-making with regard to the withholding and withdrawing of treatment. It was felt important to conduct empirical research and elicit the views of clinicians since this way 'we get to walk in other people's shoes' and their stories 'open our eyes to...ethical dilemmas and dramas surrounding life and death'.[10] There is disagreement over whether there is an ethical difference between withholding and withdrawing of medical treatment. The BMA sees no difference[11] but

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[1]Drummond MF. Resource allocation decisions in healthcare: a role for quality of life assessments? In Dowie J, Elstein A. *Professional judgment - a reader in clinical decision-making.* 1988 Cambridge University Press, Cambridge at pp436-455, at p437.

[2]One decision, known to the author from her previous career within the NHS as a microbiologist, which remained hidden from public scrutiny because the patient concerned had no living relatives was that of 'Emily'. She was 87 years old when admitted to hospital. She was then discovered to have diabetes unrelated to the admitting cause. Poor bed care led to her developing a sore on one heel which turned gangrenous. The heel was amputated. The gangrene persisted. Her leg was amputated below the knee. The gangrene persisted. She was, by then, very frail, but still mentally competent though confused by what was happening. A further amputation at the hip was carried out, ignoring her protests, and, because of her frailty, it was conducted under local anaesthetic. She died three weeks later. This thesis is dedicated to her memory.

[3]*R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055. See also: R v *R v North West Thames RHA ex parte Daniels* [1994] 109 BMLR 67; *R v North West Lancashire HA ex parte A, D & G.* [2000] WLR 977 and *Airedale NHS Trust v Bland* [1993] AC 789.

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[6]Seedhouse D. 'Core Health Services, Social Values and Democracy'. In Campbell AV, GillettG. *Ethical Issues in Defining Core Services. Discussion papers prepared for The National Advisory Committee on Core Health and Disability Support Services.* 1993 NAC, Wellington, New Zealand pp67-76 at p71.

[7]Butler J. *The Ethics of Health Care Rationing: Principles and Practices.* 1999 Cassell, London at p105.

[8]Klein R, Day & Redmayne S. *Managing Scarcity: Priority Setting and Rationing in the National Health Service.* 1996 Open University Press, Oxford at p34.

[9]Klein R, Day & Redmayne S. *Managing Scarcity: Priority Setting and Rationing in the National Health Service.* 1996 Open University Press, Oxford at p83. Since the work for this thesis commenced, Chris Ham has analysed, from the perspective of the different parties, both the Child B case and similar ones since then. See: Ham C, Pickard S. *Tragic Choices in Health Care: The case of Child B.* 1998 King's Fund, London and Ham C, McIver S. *Contested Decisions: Priority setting in the NHS.* 2000 King's Fund, London.

[10]Dula A. The Life and Death of Miss Mildred: An Elderly Black Woman. *Clinics in Geriatric Medicine.* 1994;**10,**3:419-430 at **p429**.

[11]British Medical Association. *Medical Ethics Today: Its practice and philosophy.* 1993 BMA, London at p170. The House of Lords Select Committee on Medical Ethics likewise sees no difference. *Report of the Select Committee on Medical Ethics* HL Paper 21 1994 HMSO, London.

others believe that doctors and families feel there is a difference.[12] This thesis started out with a premise that withholding and withdrawing treatment were the same but found that the 'feels different'[13] factor cannot be ignored by healthcare decision-makers wanting public backing nor can it be ignored by those who wish to analyse such decisions. Consequently, the analysis was changed from being conducted according to the outcome of the decision (immediate/imminent death; eventual death and reduced quality of life) with withholding and withdrawal decisions being considered jointly because it became evident that not only would this inappropriately validate outcomes models of resource allocation but would ignore key differences in the way decisions to withhold or withdraw treatment are made by doctors. No distinction is made between 'ordinary' treatment and 'extraordinary'.[14] Although there was a change of government at the time of conducting the empirical research a political critique has been avoided.

1.1 Research Aims and Objectives

- To investigate how decisions to withhold or withdraw potentially curative treatment from patients are made
- To identify what factors are taken into account
- To critique existing methods and proposals for resource allocation and the withholding and withdrawing of medical treatment from both adult and child patients
- To suggest how the process can be improved.

1.2 Methodology

A comprehensive literature search of books, journals and government documentation was conducted using traditional methods and internet search engines.[15] The field is constantly developing so the search for materials and analysis thereof continued throughout. The background reading enabled the issues which formed the basis of the empirical research to be identified.[16] It was decided that the most appropriate research model to investigate the views of doctors would be the qualitative style. There are three main models of sociological research which could have been employed: the experimental model; the quantitative model and the qualitative model. The experimental model, most commonly adopted when comparing different types of treatments, eg. the randomised controlled trial, was inappropriate as the purpose was not to compare one theory or method against another. A quantitative approach, typified by the making of surveys, is designed to compare and analyse large amounts of data and is the most commonly undertaken form of healthcare research. It holds great attraction as the method to employ; however, restrictions of time and resources meant rejecting this model as

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[12]Shaw A.B. Acts of commission, omission, and demission or pulling the plug. *J.Royal.Soc.Med.* 1995; **88**:18-19, at p18. See also: Campbell AGM. Baby Doe and Forgoing Life-Sustaining Treatment. In Caplan AL, Blank RH, Merrick CJ (Eds). *Compelled Compassion.* 1992 Humana Press, Totowa, New Jersey pp207-236 at p224 and Bayles M, High DM (Eds) *Medical Treatment of the Dying: Moral Issues* 1978 GK Hall & Co, Shenkman Publishers at p6 and p122.

[13]Shaw, op cit n12 at p18.

[14]Such distinctions have likewise been rejected by others: Smith DH, Veatch RM (Eds). *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying. A Report by the Hastings Center.* 1987 The Hastings Center, Indiana University Press, Bloomington and Indiapolis at p5.

[15]Occasionally, popular press articles will be referred to since this thesis will argue that it is important for the public to participate in debates about healthcare allocation so it seems proper to include these as a reflection on what topics are being debated.

[16]Medical terminology is necessarily used and a glossary of terms and their meaning is found in Appendix Four. The terminology employed is that used by Lord Walton of Detchant. Walton. Dilemmas of life and death: Part One. *J.Royal Soc.Medicine* 1995;**8**:311-315 at pp312-3.

sufficient data to enable a statistical analysis to be made could not have been generated. Also, as Daly and McDonald recognise, 'the process of categorisation and quantification necessarily imposes the researcher's assumptions and concepts onto the field of study'.[17] Hence, quantitative surveys can miss the social interaction aspect that is an important part of the doctor-patient relationship. The qualitative approach, however, enables the social interactions between the different parties in the healthcare relationship to be studied since it is 'hypothesis generating'.[18] It can be used to study patient-doctor relationships and their effect on the development of healthcare provision, and also, to study the 'cultural, historical and political circumstances' influencing the delivery of healthcare.[19] The qualitative method allows the collecting of data from diverse sources: tape-recorded interviews; reports; published studies and academic articles. The researcher should 'listen and ask questions until they understand how each group makes sense of its experience'.[20] The analysis that has been made seeks to lead to a 'maximal understanding...of the phenomena being studied'.[21] The interview setting can affect the responses given so interviews were conducted as, where, and when, the consultant suggested though the quality of the analysis is more important than 'the recruitment of the sample or...the format of the interview.[22] The known background of the interviewer can influence the responses given but the twin backgrounds of the researcher as both a healthcare professional and post-graduate law student possibly operated to neutralise this effect.[23] Some suggest that in order to judge a tradition, one must have entered it as an apprentice.[24] Several interviewees tested my medical knowledge early on and, once satisfied that I understood the medical details mentioned, they visibly relaxed and talked freely. Some commented that they would have been less willing to be interviewed if I had only had a law background since I would have been perceived as having limited understanding of their world and their subjects, which would have meant they not only had to explain their views but also explain the conditions/treatments to which those views related. Thus, with most of the consultants interviewed, the interviewer and interviewee became 'peers' which Silverman asserts is important in order to gain 'deep understanding'.[25] However, becoming 'peers' did not mean 'going native' and I attempted to maintain objectivity throughout.[26]

In order to investigate how decisions are made about continuing/discontinuing/withholding medical treatment, it was decided that consultant-level clinicians should be targeted since they would be the most experienced and are usually highly regarded within their profession. Because such studies generate large amounts of data from each individual source, most, like the one conducted for this thesis, have a small sample size. This makes it difficult to extrapolate legitimately the results found to how a larger group of similar people react in the same situation. To minimise this difficulty, it was decided to survey consultant clinicians. Thus, the information generated would be more capable of being legitimately extrapolated and generalised.[27] By targeting consultants from various specialties, it was felt possible to obtain a broader spectrum of responses which would avoid the bias that could be introduced if only high-profile conditions such as organ transplant or cancer therapy were

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[17]Daly J., McDonald I & Willis E.(Eds) Researching Health Care: Designs, dilemmas, disciplines. 1992 Routledge, London at pp8-9.
[18]Najman JM et al. Comparing alternative methodologies of social research. In: Daly J, McDonald I, Willis E. *Researching Health Care: Designs, Dilemmas, Disciplines.* 1992 Tavistock/Routledge, London at pp138-157 at p140.
[19]Ibid.
[20]Ibid.
[21]Hitchcock G, Hughes D. *Research and the Teacher.* 2nd Edn. 1995 Routledge, London at p296.
[22]Silverman D. *Interpreting Qualitative Data: Methods for Analysing Talk, Text and Interaction.* 1993 Sage Publications, London at p22.
[23]Ibid, at p95.
[24]Kuczewski MG. *Fragmentation and Consensus: Communitarian and Casuistic Bioethics.* 1997 Georgetown University Press, Washington DC at pp11-12.
[25]Silverman, op cit n22 at p22.
[26]Miles MB, Huberman M. *An Expanded Sourcebook: Qualitative Data Analysis* 2nd Edn. 1994 Sage, London at p63.
[27]Najman JM et al, op cit n18, at pp145-6.

studied. The consultants were attached to one or more of four different hospitals which were all relatively close to each other (a table showing hospital sizes is given below).[28] An attempt was made to include a large teaching hospital in a different region from the other hospitals to neutralise any possible regional bias. However, although an initial, seemingly positive, meeting with the medical director was held, attempts to follow this up by letter and telephone to gain clear agreement to my contacting consultants within the hospital received no response. Consequently, a modified approach was taken with the other hospitals. The person considered the ethics expert was identified[29] and an introductory meeting held during which the purposes and methodology of the research project were outlined. Following these meetings, each confirmed that the research raised no ethical concerns and did not require formal approval from the LREC and each gave permission for his/her name to be used when contacting consultants.[30]

Hospital	Annual Budget of NHS Trust (£ approx)	Number of Beds(approx)	Type of Hospital
A	100,000,000	1000	City General + Specialist Services
B	100,000,000	1000	City General + Specialist Services
C	150,000,000	>1,000	City Teaching General + Specialist Services
D	30,000,000	300	Town General

1.3 Data Collection

A questionnaire was designed by the author and slightly modified following scrutiny by more experienced researchers.[31] An initial trial was carried out by contacting consultants at the smallest hospital to gauge the level of interest and whether the questionnaire worked satisfactorily. The response rate was good, the interviewees provided plenty of time and much enthusiasm for the project was shown. Therefore, the format was kept the same and the next stage carried out by contacting consultants at three other hospitals. During the field work, notes were kept relating to the research forming a 'data analysis chronology'.[32]

Consultants at four hospitals in total were identified but considerably more difficulty was experienced obtaining consultant names from hospital C which had become the centre of media attention.[33] Some randomisation was introduced by writing only to every other consultant name at hospitals B and C and every third name at hospital

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[28]The table broadly outlines the characteristics of the four hospitals. Detailed descriptions will not be provided in order to prevent identification of the hospitals concerned. The information was extracted from *The IHSM Health and Social Services Year Book* 1997/98 1997 Financial Times Healthcare, London.

[29]This was usually the most senior clinician on the Local Research Ethics Committee. S/he was identified by telephoning the hospitals.

[30]Local Research Ethics Committees are charged with the role of considering the ethics of research projects which will involve human subjects and to advise the NHS body whether the project should proceed or not. LRECs must be consulted if the research involves recruiting patients; foetal material; the recently dead; access to health records or access to NHS facilities (Department of Health. *Local Research Ethics Committees* 1991 HMSO, London at paras 1.1-1.3). In fact, two of the hospitals shared an LREC as is not uncommon. Access to NHS facilities was the only relevant factor but not a necessity although, in reality, all the interviews took place on NHS premises. It was held by the ethics experts consulted for approval that the research came under the exception given to 'Enquiries and Surveys in the Public Interest where no reference to an LREC is necessary' (*Local Research Ethics Committees* Appendix A)

[31]See Appendix Three.

[32]Miles MB, Huberman M, op cit n26, at p282. This showed the timing of the sending out of the initial letter to the first hospital and subsequent responses to interview requests, the process of making appointments for interviews etc. Other items included were the initial attempts to find a 'user-friendly' way of transcribing the tapes which ended up in a long-term loan of a proper (and expensive) transcription machine.

[33]The three other hospitals had been happy to supply lists of the consultants but Hospital C was not prepared to do this which meant the pool of consultants was smaller than really appropriate for the size of the hospital. A major scandal had just hit the headlines with several doctors at Hospital C being accused of professional misconduct.

A.[34] Letters were sent outlining the nature of the research requesting time for an interview.[35] Appointments were made with those who responded affirmatively.[36] Three consultants responded by letter only setting out their views.[37] At the start of each interview, confidentiality was reaffirmed and the consultants were offered the choice of having it taped or handwritten notes made instead. Four consultants opted for the latter option and one, after a few minutes, said she felt relaxed enough to let me tape the rest which was done. The majority of interviews lasted half an hour but several lasted up to ninety minutes. Three were very short because of urgent calls upon the consultant's time so have not been used. After some of the interviews, the researcher's own reflections/comments were added to the tape.[38] Eighty-four tapes/interview notes were successfully transcribed in full resulting in a total of 375 pages of original material.[39]

Hospital	Number of letters sent	Number agreeing to interview	Response by letter only	Number of successful appointments	Number of negative responses	Percentage of positive responses (%)
A	51	36	0	36	9	71
B	36	20	1	19	1	61
C	37	21	1	18	4	59
D	26	18	1	17	3	73
Totals	150	95	3	88	17	65

1.4 Data Analysis

Although data analysis was carried out after completion of the surveys, informal data analysis naturally occurs during the interviewing process in the sense that the researcher attempts to rationalise what is being said in light of existing knowledge and understanding. A semi-structured interview technique was utilised but to minimise any distortion that might occur as a result of premature informal analysis, the format was kept as consistent as possible with further questioning restricted to clarification of statements made.[40] Some interviewees were unsure whether I was only looking for comments about resource allocation when the questioning moved from the early questions regarding the effect of resources on their practice to questions regarding the withholding and withdrawing of medical treatment from individual patients. This indicated a minor flaw in the design of the questionnaire but one that was easily overcome by clarification of the question. An awareness was maintained that prior opinion and the influence of the earlier interviews could prevent totally unbiased analysis and a concerted effort was made to approach the interviews 'without any advance

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[34]This was done by selecting within the specialties rather than alphabetically. At Hospital D, the pilot hospital, letters were sent to all the consultants. Some consultants were attached to more than one of the hospitals.

[35]See Appendix One.

[36]It is recognised that this can be a source of research error in that the inaccessibility of some consultants could be due to excessive workload and/or uncooperativeness and valuable and/or balancing insights could consequently be missed: Miles MB, Huberman M, op cit n26, at p264.

[37]This option had not been offered but the ones who did this were too busy in the near future to offer an appointment but wished to make their views known. Only one of these has been used (D1) because it followed an extensive telephone discussion during which we went through the questionnaire but, at her request, she then followed up with a letter setting out her views upon further reflection.

[38]The comments added later included ones which explained interruptions such as fire-alarms being set off and also where the interview took place if it was not the consultant's own office since this might have prevented the consultant feeling relaxed etc. No attempt to interpret body language was made. None of the factors which were noted seemed to have distorted the interview in any way.

[39]Including two pages of comments extracted from the letter sent by consultant D1. One of the tapes had inadvertently been recorded over by a subsequent interview. A couple of tapes suffered damage and had some sections that were inaudible, however, mostly they were usable, even the one where a faulty fire alarm kept going throughout the interview.

[40]Silverman D, op cit n22 at p93, accepts Selltiz' rules and taboos about interviewing: 'Interviewers should ask each question precisely as it is worded and in the same order it appears on the schedule. They should not show surprise or disapproval of an answer, offer impromptu explanations of questions, suggest possible replies or skip certain questions.'

knowledge or assumptions'.[41] The questions were designed not to 'lead' and were mostly open questions which enabled the interviewee to interpret them freely. The semi-structured interview was favoured because it allows the interviewer to clarify issues and probe producing in-depth material.[42] Disadvantages include the inhibitions structuring imposes on the way ideas are normally exchanged but good interviewing skills on the part of the researcher can establish the rapport necessary to 'socialise' the interview.[43] Although interviewing can be seen as a 'masculine paradigm'[44], maintaining professionalism can avoid gender-related distortions.[45] After the 'formal' interview had ended and the tape-recorder turned off, several of the consultants then talked more freely and related some controversial anecdotes. A note was made of the content of this discussion on leaving the interview premises. However, this information has not been drawn upon as part of the data for this thesis because it would be subject to inaccuracies in recording and possible bias since the author was able to engage in debate about the topic.[46]

In order to analyse the data, 'patterns, themes, consistencies and exceptions to the rule' were sought.[47] This meant engaging in detailed conceptual analysis of the interviews, reading each several times and noting the themes and patterns that began to emerge whilst guarding against distortion.[48] Each transcript was analysed question by question with typical and atypical responses noted.[49] The analyses and the interviews were all conducted by the same person which some consider necessary for purity.[50] These were then appraised in the light of preceding discussions regarding current legal and ethical opinion in order to sensitise the issues. Awareness was maintained that the transcripts could reflect both 'true accounts' and 'situated narratives'[51] but were taken as 'informed statement(s) by the person whose experiences are under investigation'.[52] Direct quotations were extracted from the transcripts of the interviews in order to illustrate the analysis but care was taken to ensure that the quoted material had coherence with the rest of the interview to avoid erroneous misrepresentation.[53] Miles and Huberman note that the researcher operating alone, as in this case, 'runs several risks of generalising wrongly from specific instances'.[54] In particular, care has been taken to avoid 'drawing inferences from nonrepresentative processes' due to 'nonrepresentative...events;...good fit into emerging

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[41]The approach taken was as objective as possible to overcome the researcher's own views. It accorded closely with that described by Häggman-Laitila: Häggman-Laitila A. The Authenticity and Ethics of Phenomenological Research: How to overcome the researcher's own views. *Nursing Ethics* 1999;**6,**1:12-22 at p12.

[42]Hitchcock G, Hughes D. *Research and the Teacher: A Qualitative Introduction to School-based Research.* 2nd Edn. 1995 Routledge, London at p157.

[43]Ibid, at pp158-160.

[44]Oakley A. *Essays on Women, Medicine and Health.* 1993 Edinburgh University Press, Edinburgh at p222.

[45]See: Hitchcock & Hughes, op cit n42, at p166 and Oakley, op cit n44 at pp221-242. It is beyond the scope of this thesis to investigate in the light of Oakley's thesis whether a satisfactory interview can be conducted by a woman researcher 'interviewing' males of a traditionally dominant group such as doctors.

[46]There was also a tacit understanding that such comments were 'off the record' and consequently not to be used and this has been respected although it could be argued that since the purpose of the meetings was to elicit information about how doctors make decisions nothing was off-record.

[47]Hitchcock & Hughes, op cit n42, at p296.

[48]The approach taken was based on that advocated by Miles and Huberman who suggest the following tactics should be employed: 'Noting patterns, themes...seeing plausibility and clustering...making metaphors...counting...making contrasts/comparisons...partitioning variables...subsuming particulars into the general...factoring...noting relations between variable...finding intervening variables...building a logical chain of evidence...making conceptual/theoretical coherence'. Miles MB, Huberman M, op cit n26, at pp245-6.

[49]Lewando-Hundt G et al. How to do (or not to do)...: Comparing manual with software analysis in qualitative research: undressing Nud.ist. *Health Policy and Planning* 1997;**12,**4:372-380.

[50]Ibid, at p15.

[51]Silverman, op cit n22 at p108.

[52]Ibid, at p107.

[53]Silverman has repeatedly pointed out the danger that the researcher may use 'favoured examples to make a point and thus to tell a"story" about the data that is rhetorically rather than scientifically convincing'. Silverman D. Applying the qualitative method to clinical care. In: Daly J, McDonald I, Willis E. *Researching Health Care: Designs, Dilemmas, Disciplines.* 1992 Tavistock/Routledge, London pp176-188, at p185. Also, Silverman D. Telling Convincing Stories: A Plea for Cautious Positivism in Case-Studies. In: Glassner B, Moreno J (Eds) *The Qualitative-Quantitative Distinction in the Social Sciences.* 1989 Kluwer, Dordrecht at p57-77.

[54]Miles MB, Huberman M. *An Expanded Qualitative Data Analysis* 2nd edn. 1994 Sage, London at p264.

explanation; holistic bias'.[55] To maintain balance, contrasting cases have been identified and the population of senior decision-makers (consultant grade doctors) was randomly sampled. Conclusions will not be drawn as to whether one specialty has differing views from another since the number of consultants within a particular discipline was necessarily small.[56] Thus, the analysis will consider how consultants in general make decisions about withholding and withdrawing treatment. At times it will be appropriate to compare and contrast individual statements and, occasionally, anecdotal evidence (patient case histories) will be reported. Statistical analysis of the number of consultants stating certain views has not been carried out because, overall, the numbers involved were small and from disparate specialties although, occasionally, comments/numbers have been included as to whether a majority or minority of responses reflected a certain approach.[57] As Silverman holds, 'work that is not based on experimental or statistical methods need not be anecdotal'.[58]

1.5 Thesis Structure

Research aims, objectives and methodology are outlined in this chapter (one). The next chapter (two) examines British state-funded healthcare provision in the 1990s and identifies the nature of the conflicts. Chapter three describes how doctors make decisions to withhold medical treatment whilst chapter four describes decisions to withdraw treatment. The different factors taken into account by doctors when making decisions to withdraw treatment as opposed to non-commencement of treatment are identified. At this stage it is possible to start to identify what criteria any normative proposals regarding treatment decisions must fulfil. The next two chapters investigate and evaluate models others suggest are appropriate. Chapter five examines politico-economic, medical and 'ethical' models for allocating resources and determining who receives or does not receive treatment. It establishes that these models are isolated from each other and only produce partial solutions to the problem of when to treat or not to treat. Chapter six explores how the law determines whether treatment should be given or not and identifies the extent to which medical opinion dominates judicial reasoning. This has the consequence that elderly and learning/physically disabled patients seem insufficiently protected against discriminatory practices. Chapter seven critiques key reform proposals that have been made since the empirical research for this thesis was conducted. It concludes that these, like the existing models described in chapters five and six, fail to fully resolve the problems identified in chapters two, three and four. Therefore, in the final chapter (eight), recommendations for ways to improve decision-making are made and a new process is proposed.

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[55]Ibid.

[56]It is probable, though, that differences between specialties and hospitals, partly due to the culture of the specialty and organisation and partly due to other factors, exist. For instance, see Pijnenborg L et al: Withdrawal or Withholding of Treatment at the End of Life - Results of a Nationwide Study. *Arch.Intern.Med.* 1995;**155**:286-292. They report that surgeons make the most non-treatment decisions and cardiologists the fewest. A list of consultants by specialty and hospital size can be found in Appendix Two. Each has been given an individual code which will be used whenever a direct quote from the interview with that consultant is made. The four hospitals included are labelled A-D, and then consultants within each are numbered.

[57]There are conflicting views as to whether statistical analysis should be carried out: Najman, op cit n18, at pp146-7, suggests it is appropriate. In contrast, Silverman believes that 'quantification can arbitrarily impose categories on complex, naturally occurring phenomena'. Silverman D. Applying the qualitative method to clinical care. In: Daly J, McDonald I, Willis E. *Researching Health Care: Designs, Dilemmas, Disciplines.* 1992 Tavistock/Routledge, London at p185. Miles and Huberman, op cit n54 at p253, hold that qualitative researchers should resort to numbers only for the following reasons: 'to see rapidly what you have in a large batch of data; to verify a hunch or a hypothesis; and to keep yourself analytically honest, protecting against bias'.

[58]Silverman, op cit n57 at p187.

1.6 Limitations of the Research

Only a limited number of doctors/hospitals were involved and no GPs, health authority purchasers or patients/relatives were interviewed. Physical illness was concentrated on rather than mental illness.

CHAPTER TWO

BRITISH STATE HEALTHCARE PROVISION IN THE 1990's

The NHS was created in 1948.[1] It was intended to achieve the 'establishment...of a comprehensive health service designed to secure improvement in the physical and mental health of the people...and the prevention, diagnosis and treatment of illness.'[2] Financial barriers to healthcare should disappear.[3] Justice was the underlying principle though many have questioned how equal access to healthcare is.[4] The promise was that 'every man and woman and child can rely on getting all the advice and treatment and care which they need' and they shall get 'the best medical and other facilities available'.[5] Since its conception the NHS has witnessed advances in medicine and changes in social attitudes which have tested its ability to provide universal healthcare provision at a satisfactory, and fiscally sustainable, standard.[6] Major reforms were introduced at the start of the 1990s to try to address some of the challenges facing the NHS. These were modified towards the end of this period following the replacement of an eighteen year Conservative administration by a Labour government. This chapter examines the NHS as it was at the time of conducting the research for this thesis and the changes introduced following the 1997 election. The problems besetting doctors as decision-makers are identified. The following chapters will then examine how individual decisions to withhold or withdraw medical treatment are made.

2.1 Background to the 1990 Reforms

Although based on a 'pay as you go' system[7] it was obvious very early that NHS demand would outstrip affordable supply.[8] Diseases of old-age became more common.[9] Childhood deaths became rare and were accompanied by a sense that the NHS had let the child down.[10] Critics point out that '(m)edical advance has been a major driver of increased healthcare expenditure over the past few decades'.[11] Doctors are blamed because 'the major - and most expensive - part of medical technology as applied today appears to be more for the satisfaction of the health professionals than for the benefit of consumers of healthcare.'[12] By 2001, 8% of the population is expected to be 'very elderly' (ie over 75 years) using nine times the healthcare resources a

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[1]By the National Health Service Act 1946. The founding principles are found in the 1944 White Paper: *A National Health Service*. (Cmnd 6502) Ministry of Health: Sir John Hawton.1944 HMSO, London.

[2]The National Health Service Act 1946. Ch81 Part 1 Section 1.

[3]Although long-stay residential and nursing home care was means-tested. Responsibility for both medical care and residential care rested with the Medical Officer of Health.

[4]See for instance, AV Campbell: *Medicine, Heath and Justice*. 1978 Churchill Livingstone, London and Daniels N: *Just Healthcare*. 1985 Cambridge University Press, Cambridge. Also, Attfield R: The global distribution of healthcare resources. *J.Med.Ethics* 1990;**16**:153-6.

[5]Klein R: *The New Politics of the NHS*. 1995 Longman, London at p9.

[6]Rivett G. *From Cradle to Grave: Fifty years of the NHS*. 1998 Kings Fund, London. See pp213-215. See also: Butler J. *The Ethics of Health Care Rationing: Principles and Practices*. 1999 Cassell, London at p232.

[7]Which meant that income raised through national insurance or taxation from those with earnings or income above a certain level, is immediately paid out to support those whose income is non-existent or too low to enable them to purchase the necessities of life, including healthcare.

[8]The Guillebaud Report. The Report of the Committee of Enquiry into the Cost of the National Health Service. Chairman: CW Guillebaud. (Cmnd 9663) HMSO, London.

[9]Department of Health. *The National Health Service: A Service with Ambitions*. 1996 The Stationery Office, London at p35.

[10]As evidenced by the media coverage of the *Child B* case: *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.

[11]Department of Health, op cit n9 at p36.

[12]Abel-Smith B: *Value for Money in Health Services* 1976 Heinemann, London at p221.

working-age person uses.[13]

Early reforms of the NHS meant that the many tiers and increased number of administrators complicated planning and led to a dissociation from the local community never fully resolved since.[14] RAWP (the Resource Allocation Working Party) recommended that funding to Regional Health Authorities should firstly be based on the population they served and then adjusted to take account of local variations regarding standardised mortality ratios, national age and gender specific hospital usage rates, the additional costs of providing healthcare in London compared with the rest of the country and the flow of patients between different regions.[15] The intention was to reduce regional inequalities but the RAWP formula was adjusted to allow poorer regions to catch up with wealthier ones rather than lowering standards in better-funded regions. It had a major effect on the London area which had been previously well-funded with the result that in the 1980s, London health authorities had to make cuts in services.[16] The NHS is designed not only to deliver medical care to individuals but also to 'allocate and reallocate resources' hence, reforms focus on improving management.[17] In 1979, the NHS aimed to promote individual health; provide equality of entitlement and access to health services; provide a broad range of services free at the time of use; satisfy reasonable expectations and be responsive to local needs.[18]

Such objectives, even with the omission of improving the nation's health, are difficult for any government to achieve regardless of political persuasion. Structural reforms based on *Patients First*[19] were introduced to reflect 'social geography' more than local authority boundaries. Sir Roy Griffiths criticised the lack of accountability within NHS management and 'consensus management'.[20] His recommendations resulted in the appointment of managers accountable for improving efficiency but they lacked powers to restrict the spending of clinicians who kept their 'right of clinical freedom' agreed at the start of the NHS. In 1988, a distinction was made between policy aims and service objectives[21] to clarify how health authorities use their allocated funds.[22] Emphasis was placed on improving the health of the population.[23] GP and dentist contracts were reformed with financial incentives introduced to improve patient health/prevent disease.[24] *Working for Patients*, presented changes to increase efficient use of resources and address management problems.[25] *Caring for People*[26], responded to the concerns of the 1988 Griffiths Report.[27] RAWP was modified to enable resources

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[13]Government Statistical Service. *Health and social service statistics for England.* 1994 HMSO, London. See also, Skedelsky R: Cuts to benefit the nation. *The Sunday Times* 11 February 1996.

[14]Sir Alec Merrison. *Royal Commission on the National Health Service.* (Cmnd 7615) 1979 HMSO, London. He was the vice-chancellor of Bristol University and was asked to conduct the investigation in 1976. See also: Kelly M, Glover I. In search of health and efficiency: the NHS 1948 - 1994. In Leopold J et al (Eds) *Beyond Reason? The National Health Service and the Limits of Management.* 1996 Stirling Management Series, Avebury at p19.

[15]RAWP: *Sharing Resources for Health in England.* 1976 HMSO, London.

[16]Baggott R. *Health and Healthcare in Britain.* 1994 McMillan Press Ltd, Basingstoke at p187.

[17]Levitt R, Wall A. *The Reorganised National Health Service.* 3rd Edn. 1984 Croom Helm, London at pp17-18.

[18]Sir Alec Merrison. *Royal Commission on the National Health Service* (Cmnd 7615) 1979 HMSO, London at p9, para 2.6.

[19]Department of Health and Social Security. December 1979 HMSO, London.

[20]Sir Roy Griffiths. *The NHS Management Inquiry.* October 1983. HMSO, London.

[21]Service objectives included the introduction of the Patient's Charter in 1991 which set out what patients should expect in terms of waiting times, cancellations and handling of complaints.

[22]Department of Health. *Health of the Population: Responsibilities of Health Authorities.* HC(88)64 1988 HMSO, London.

[23]Secretary of State for Health. *Promoting Better Health* (Cm 249) 1987 HMSO, London. Guidance was issued in the following documents: *Health Services Development. Resource Assumptions and Planning Guidance* (HC(88)43, 1988 & HC(89)24, 1989) and *NHS Priorities in 1991/2* (EL(90)154, 1990), all HMSO, London.

[24]Benzeval M et al. *Tackling Inequalities in Health: An Agenda for Action.* 1997 Kings Fund, London. In particular, see p100 for a critique of the payments to GPs in deprived areas.

[25]Secretary of State for Health. *Working for Patients* (Cm 555) 1989 HMSO, London. A critique of the reforms proposed in this document can be found in: Maynard A: *Whither the NHS.* 1989 Centre for Health Economics, York.

[26]Secretary of State for Health. *Caring for People.* (Cm 849) 1989 HMSO, London.

[27]Sir Roy Griffiths. *Community Care: Agenda for Action.* 1988 HMSO, London.

to be allocated on the basis of the size of the RHA[28] and the age and health of residents.[29] Local authorities were to identify healthcare needs of the local population and formulate community care plans with the NHS authorities. Emphasis was placed on 'targeting' resources to appropriately meet a person's assessed needs. The difficulty of separating 'needs' from 'wants' is a perennial problem and the failure to account for 'socioeconomic determinants of the demand for healthcare' created problems.[30] Ward closures; the failure of government to fund NHS pay awards fully leaving health authorities to make up the difference; the effects of RAWP and the death of a patient whose operation was cancelled five times led to the reforms of 1991.[31]

2.2 The 1990 Reforms

Government saw the NHS as 'gridlocked' with healthcare professionals resisting attempts to improve efficiency.[32] The reform proposals demonstrated a belief that 'competition leads to efficiency' and 'professions should be subject to managerial accountability and control'.[33] They could be interpreted as a natural progression of society 'from status to contract'.[34] However, the move towards interpreting healthcare relationships as fiduciary[35] suggests that a contract model is inappropriate. The key reforms were the introduction of a new system of contractual funding; new methods for allocating resources and changes to strengthen management and control clinical activity.[36] An ever-increasing role for private[37], charitable and voluntary sector provision was envisaged with tax incentives for individuals taking out private health insurance.[38] There were proposals that charges should be introduced for those who could pay.[39] The proposals were based on the 'public contract' model of healthcare adopted by several European countries.[40] The idea was that publicly funded healthcare should be delivered via a decentralised market economy approach replacing state/professional paternalism with new emphasis on individual autonomy.[41]

The National Health Service and Community Care Act 1990 came into force in 1991 after a 'stormy passage'[42]

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[28]Regional Health Authority.
[29]See: Ham C: *The New National Health Service: Organization and Management.* pp51-7.1991 Radcliffe Medical Press Ltd, Oxford and Sheldon TA et al: Weighting in the dark: resource allocation in the new NHS. *BMJ* 1993;**306**:835-9.
[30]Benezeval M et al op cit n24 at p97.
[31]Baggott R, op cit n16 at pp173-4.
[32]Ibid, p176.
[33]O'Hara SP. The NHS - Past, present and future. *Biomedical Scientist* 1996:605-7 at p605.
[34]Hughes D, Dingwall R. Sir Henry Maine, Joseph Stalin and the Reorganisation of the National Health Service. *J.Social Welfare Law* 1990,**5:**296-309 at p296.
[35]Harrington JA. Privileging the medical norm: liberalism, self-determination and refusal of treatment. *Legal Studies* 1996,**16,**3:348-367 at p364-6.
[36]National Health Service and Community Care Act 1990.
[37]The first PFI (private finance initiative) funded hospital, built near Dartford, Kent by Tarmac, opened September 2000. Others are set to open at Bromley and Carlisle. The Dartford hospital will be leased to the NHS for the first 25 years and at the end of that time, there is an option for ownership to pass from Tarmac to Dartford and Gravesham NHS Trust. (personal communication). This means that just as the building is starting to age and need maintenance and modification to suit healthcare provision from 2025 onwards, ownership may pass to the state - a situation not dissimilar from that faced by the NHS at its inception. There were also suggestions that healthcare charges should be introduced for those who could afford to pay them (Healthcare 2000. *UK Health and Healthcare Services: Challenges and Policy Options.* 1995).
[38]The Health and Medicines Act 1988 gave health authorities the right to sell land, services etc. at the market rate and the National Health Service and Community Care Act 1990 enabled the introduction of Private Finance Initiatives(PFI) to attract private funding into healthcare. £5 billion worth of projects was agreed before the change of government: Butler J. The privatisation of the National Health Service. J. Royal Soc. Medicine 1997;**90:**3-7 at p5.
[39]Healthcare 2000. *UK Health and Healthcare Services: Challenges and Policy Options.* 1995 Healthcare 2000, London.
[40]Hurst JW. Reforming healthcare in seven European countries. *Health Affairs* 1991;**10,**3:7-21.
[41]Edgar A. Healthcare Allocation, Public Consultation and the Concept of 'Health'. *Healthcare Analysis* 1998;**6:**193-8 at p193.
[42]The BMA spent £3 million on a campaign opposing the reforms and the loss of the medical veto on changes to the NHS. Timmins N. *NHS 50th Anniversary: A history of the NHS* 1996 *The Financial Times.* Reprinted 1998 NHS 50, NHS Executive, Leeds. It commissioned its own report on the proposals. BMA. *Special Report on the Government's White Paper 'Working for Patients'.* 1989 BMA, London.

not least because of its heavy reliance on 'delegated legislation'.[43] The strength of opposition meant the reforms were more gradual than envisaged.[44] An 'internal market' within the NHS was created despite the lack of pilots to test the philosophy first. As Baggott later pointed out, Williamson, in 1975, had shown that markets were 'less effective than hierarchies' in circumstances such as those that exist in healthcare: 'small numbers of specialist providers; where great uncertainty and technical complexity exist; where providers or purchasers can be tied into contracts for long periods; where there is imperfect knowledge about costs; and, where scope for 'opportunistic behaviour' exists'.[45] Research into treatment outcomes and health economics produced increasing emphasis upon cost-effectiveness ('opportunity costs').[46] Measurements of health outcomes became 'central to assessing the performance of health authorities and NHS Trusts'.[47] Cooperation between the different agencies was essential for the system to work effectively but in reality proved difficult to achieve. Local authorities were given responsibility to purchase residential care and monitor its provision. This, combined with the gradual erosion of state funding, means more old people have to fund their own care.[48] Patients block hospital beds due to a lack of local authority provision.[49]

The 'purchaser:provider split' was introduced with Health Authority 'purchasers'[50], whose role was 'to purchase treatment from whichever provider can offer the most appropriate and cost-effective package', and District General Hospitals 'providers'. Each provider was perceived to be in competition with its neighbour. Treatment 'episodes'[51] or 'packages of care' were to be costed and tenders submitted to purchasers just as businesses tender for service contracts. However, these 'contracts' were not intended to be enforceable under normal contract law[52] and the situation was likened to pre-perestroika Soviet law.[53] Public and private providers were theoretically competing fairly[54] but the private sector could set up loss-leader services to gain entry to the market.[55] There was active encouragement for hospitals and ambulance services to take quasi-private status as NHS Trusts to gain greater autonomy.[56] The structure of the NHS was changed to strengthen the position of managers.[57] The Secretary of State for Health, ultimately accountable to parliament for the

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[43]Hughes D. The Reorganisation of the National Health Service: The Rhetoric and Reality of the Internal Market. *Modern Law Review* 1991,**54:**88-103 at p88. The same criticism can be made regarding the use of 'Henry VIII clauses' in the 1999 Health Act.

[44]Baggott R, op cit n16, at p188.

[45]Ibid, at p181.

[46]Department of Health. *Primary Care: Delivering the Future.* December 1996. The Stationery Office Ltd, London at p34.

[47]Department of Health. *The National Health Service: A Service with Ambitions.* November 1996. The Stationery Office Ltd, London at p45.

[48]Butler J. The privatisation of the National Health Service. J. Royal Soc. Medicine 1997;**90:**3-7 at p5. The changes were made because the cost of funding residential care had risen from £39 million in 1982 to £2.5 billion in 1993: Health Committee. *First Report: Long-Term Care: NHS Responsibilities for Meeting Continuing Healthcare Needs.* HC19-1 para.15. 1995 HMSO, London.

[49]Department of Health. *The new NHS Modern Dependable* (Cm3807). December 1997. The Stationery Office, London.

[50]Previously, the Health Authorities had run the hospitals directly.

[51]An 'episode' of care might be loosely defined as the care given to an individual patient for an individual healthcare need. This can lead to 'creative' accounting in that when a patient is transferred from one consultant to another within a hospital, the first consultant is credited with having completed a treatment episode and a new, separately chargeable episode then begins with the second consultant.

[52]Jacob JM. Lawyers go to hospital *Public Law* 1991, 255-281.

[53]Hughes D, Dingwall R, Sir Henry Maine, Joseph Stalin and the Reorganisation of the National Health Service. *J.Social Welfare Law* 1990,**5:**296-309 at pp304-5.

[54]A new system of charging for capital was introduced to encourage better use of capital assets and recognition of their costs. This meant that when NHS providers tender for contracts they did so on an even basis with private providers who had always had to include elements for capital costs within their tenders. Auditing of accounts was moved to the Audit Commission for Local Authorities and the National Health Service: National Health Service and Community Care Act 1990 s20.

[55]Tenders could be sought for all elements of hospital care from providing the catering, laundry or cleaning services to providing pathology services and hip replacements. One example the author knows of from her previous experience in pathology is of a Cornish hospital which lost much of its biochemistry work to a private laboratory based in South Wales which used motorbike couriers to transport specimens several times a day from the local GPs to Wales and provided the GP surgeries with computer links directly to the laboratory for instantaneous transfer of results.

[56]Hospitals taking trust status would cease to be accountable to the DHAs and would be directly accountable to central government. The concept of Trust status was never satisfactorily explained. The Trusts did not fit the usual legal understanding of what a 'trust' is but nor did the 'contracts' between District Health Authorities and NHS Trust fit into the normal concept of a 'contract'. See: Hughes D op cit n43 at pp90-92.

[57]Under the Secretary of State and the Department of Health, the next tier comprised, as separate entities, the Special Health Authorities, the Regional Health Authorities and the NHS Trusts. These are directly accountable to the Secretary of State and include the 8 London teaching authorities, the NHS Training Authority and the Mental Health Act Commission. The AHA administrative tier was abolished.

provision of healthcare, was placed in charge of the Department of Health which, together with a policy-making unit, the NHS Executive, and the Management Executive was expected to deliver clear guidelines for NHS operations and expenditure. There were slimmed-down, more business-like DHAs and Family Health Services Authorities with reduced lay input.[58] The number and persuasiveness of Community Health Councils was reduced, seemingly at odds with the credo of 'consumerism'.[59]

Purchasers had to assess the healthcare needs of their local population and determine what, and how many, treatments to purchase whereas before, they were allocated money to provide services within their hospitals. At first, many purchasers left allocation of funds to doctors and opportunities for rational planning were missed.[60] Purchasers lacked expertise and skills.[61] Contracts fell into three main types: block contracts (eg for maternity care where it is impossible to predict demand), cost and volume contracts (a basic level of treatment is purchased and extra payments are made for treatment above this level) and cost per case contracts where a fixed price is paid for each case (often used for expensive treatment and extra-contractual referrals eg. heart transplants).[62] Purchasers had little freedom since they were expected to meet government targets on national priorities.[63] In some regions, clinicians were involved in agreeing protocols for referral into the system.[64] As Klein says, 'demand for healthcare is what the medical profession makes it'[65] raising a fundamental question as to whether health professionals should have a major role in resource allocation. There was a gap between 'aspirational priorities' and the financial commitments made.[66] Some consider gaps unavoidable.[67] The amount available for purchasers to spend held potential for 'blanket' exclusions of certain patients who might otherwise benefit from treatment[68] with little redress available to individuals since judges will not interfere with 'clinical' decisions and the Ombudsman, to his dissatisfaction, was precluded by statute from so doing.[69] 'Postcode' rationing became reality.[70]

There was also injustice caused by the differing amounts charged privately by providers.[71] There was little

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[58]1990 Act s1; Sch.1, paras. 2 & 3. Selection bias towards certain backgrounds and social standing remained unaddressed possibly because it was efficient because of the articulateness of those chosen. 'Alienation' occurred as a result. Randall A. In *Healthcare: Resources, Choices and Decisions St Catherine's Conference Report No37* 1993 The King George VI and Queen Elizabeth Foundation of St Catherine's Cumberland Lodge, Windsor at p13.

[59]BMA. *Special Report on the Government's White Paper 'Working for Patients'.* 1989 BMA, London at para. 8.7. There was no obligation on an NHS Trust to open its meetings to CHC representatives. Similarly, health authorities no longer needed to have local authority representatives on their boards leading to further distancing of health from social care.

[60]Baggott R, op cit n16 at p187.

[61]Klein R. Why Britain is Reorganizing its National Health Service - Yet Again. *Health Affairs* 1998;17,4:111-125 at p117.

[62]Shepherd J et al: Privatising the NHS: dentistry paves the way. *BMJ* 1996;**312**:922-3. See also: Baggott R. *Health and Healthcare in Britain.* 1994 McMillan Press Ltd, Basingstoke at p187.

[63]The UK is a signatory to the WHO document, *Targets for Health for All* as discussed in Smith A, Jacobson B (eds). *The Nation's Health: a strategy for the 1990s* 1988 King's Fund for London, London at p119. See also the WHO Ljubljana Charter reproduced in *BMJ* 1996; **312:**1663 with discussion at 1622-3.

[64]For instance, guidelines were drawn up for referrals for D&C operations in Buckinghamshire: Holton S, Needham G. *Successful purchasing:from information to action.* 1995 King's Fund College, London.Case study 3 p17-22.

[65]Klein R. Dimensions of rationing: who should do what? *BMJ* 1993;**307:**309-311.

[66]Klein R, Day P & Redmayne S. *Managing Scarcity: Priority Setting and Rationing in the National Health Service.* 1996 Oxford University Press, Oxford at p56.

[67]Butler J. *The Ethics of Health Care Rationing: Principles and Practices.* 1999 Cassell, London at pp9-11 and pp16-39.

[68]For instance, regarding whether to resuscitate or not. Smith E et al. Resuscitation Status of the Elderly. *J.Roy.Coll.Physicians* 1992;**26:**377. Similarly, few hospitals offer speech therapy to those over 65 years of age and physiotherapy treatment may be available only on a very limited basis to those over 70 years.

[69]See, for example: Report of the Health Service Commissioner. October 1993 - March 1994 HMSO, London. Case No W711/92-93 - Refusal to fund in-vitro fertilisation treatment. p111-116. He has now been given the authority to investigate clinical decisions as part of increasing clinical accountability.

[70]See, for instance, Audit Commission. *United they stand: Coordinating Care for Elderly Patients with Hip Fractures.* 1995 HMSO, London.

[71]In February 1996 Chelsea and Westminster Hospital was eventually cleared of a charge of breaching NHS rules by charging only £800 per treatment cycle (cost price) compared with the £1500-£2000 charged by most private clinics. *The Times* 21 February 1996.

incentive for providers to reduce costs since their potential to increase their market share was limited.[72] Despite their 'trumpeted'[73] freedom NHS Trusts were restricted by 'political expediency and public expenditure considerations'.[74] There was a lack of guidance leading to uncertainty which, coupled with a fragmented approach and resource constraints made it 'difficult to offer comparable levels of care across similar services'.[75] GP practices could elect to become 'GP Fundholders'[76] which meant that, not only did they provide primary care but they were allocated funds to directly purchase treatment from providers like the DHAs but enhanced per capita payments meant the DHAs were at risk of being starved of funds.[77] Patients were removed from GPs lists for causing the doctor to miss target payments.[78] There is also a paradox in that doctors were not to be trusted to use money wisely within hospitals yet GPs were considered capable of handling large sums of public money wisely despite the lack of training.[79] The argument that they were in touch with the local population, and so could allocate resources more appropriately, was undermined by the manipulativeness of individual patients and the failure of GP Fundholders to place 'health for their patients'[80] before structural improvements to their privately owned premises.[81] Controlling doctors through financial incentives was seen as vital despite the evidence that most are motivated by commitment to a 'caring, high-quality health service' not money.[82] Emphasis was placed on clinicians becoming more aware of financial issues and 'opportunity costs'.[83] More non-clinical managers came in to supply the necessary business skills thereby increasing administration costs[84] and contributing to demoralisation within the NHS.[85] Some doctors took on the role of both manager and clinician and tensions developed.[86] Good working relationships dissolved as competition and distrust became paramount in an effort to overcome the difficulty that there was often 'no real choice' over where to obtain services, a problem recognised by the government prior to introducing the reforms.[87] Contracts were short-term so long-term service development suffered.[88] The reforms became 'a major contributor to the financial pressures on core and emergency NHS hospital services'[89] possibly because in 'a free market...supplying what the patient wants, rather than what the patient actually needs, will frequently result in greater reward'.[90]

The modification of RAWP led to anomalies such as psychiatry having targets to reduce suicide but funds were

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[72]Mulholland G, McAllister D. The Quasi Market in Health Care: Pre-requisites, Problems and Prospects. *Public Policy and Administration* 1997;**12**,1:21-33 at p31.

[73]Corby S, Mathieson H. The National Health Service and the limits to flexibility. *Public Policy and Administration* 1997;**12**,4:60-72 at p61.

[74]Ibid, at p67.

[75]Broderick A. Ethical Considerations in Community Care: Implications for Policy and Service Provision. *Public Policy and Administration* 1997;**12**,1:34-52 at p50.

[76]Initially, they had to have more than 9,000 patients but the number of patients was soon reduced to 7,000.

[77]The money allocated is deducted from the amount allocated to the DHA. In theory, it should mean that an equal amount of money is allocated per person within a certain district. However, as part of the incentives to encourage 'opting-out' by GPs, an increased amount per capita has been allocated to fund-holders raising fears that if too many GPs became fund-holders in a certain area, the DHA would be left with no money to purchase care for patients of non-fund-holding GPs.

[78]Rogers A et al. "If a patient is too costly they tend to get rid of you:" The impact of people's perceptions of rationing on the use of primary care. *Health Care Analysis* 1999;7:225-237.

[79]Schwartz L et al. Rationing Decisions: From Diversity to Consensus. *Health Care Analysis* 1999;7:195-205.

[80]Audit Commission: *Fundholding: the main report.* The Stationery Office, London 1996.

[81]Keeley D. General practice fundholding and healthcare costs. *BMJ* 1997; 315:139. Keesley reports that GP Fundholders were permitted to spend money saved on patient care on 'other ways of enhancing services to patients' with the result that in 1995-6 'fundholders in England spent 81% (of the saved money) on premises, materials and equipment'.

[82]See Baggott R, op cit n16 at pp183-4.

[83]This is the approach being taken by Cambridge and Huntingdonshire HA. Thornton S (Chief Executive) *Response to Consultation on the Annual Plan 1997/8.* February 1997 Cambridge and Huntingdonshire HA, Cambridge.

[84]Paton C. Present dangers and future threats: some perverse incentives in the NHS reforms. *BMJ* 1995;**310:**1245-8.

[85]Sorell T. Morality, consumerism and the internal market in healthcare. *J.Med. Ethics* 1997;**23:**71-6 at p72.

[86]See, for instance, Bruggen P. *Who Cares? True stories of the NHS reforms.* 1997 Jon Carpenter Publishing, Charlbury.

[87]Hughes D et al op cit n53, at p298.

[88]Paton C, op cit n84 at p1245. Developments that did occur were often associated with the 'cosmetics' of business so as to appear attractive to 'consumers'.

[89]Keeley D. General practice fundholding and healthcare costs. *BMJ* 1997; 315:139.

[90]Persaud RD. What future for ethical medical practice in the new National Health Service. *J.Med.Ethics* 1991,17:10-18 at p16. See also, Klein et al who report that GP fundholding produced no reduction in referral rates: Klein et al, op cit n60 at p85.

allocated on the mortality rates in different regions. Rationing of healthcare seemed more common and/or more apparent and less in line with popular opinion.[91] Money was expected to follow patients but failed to do so.[92] Less choice about where to refer patients resulted.[93] Giving the DHA control over extra-contractual referrals (ECRs) produced 'low visibility rationing'.[94] It gave them control over where, or if, the patient was treated whereas, before, doctors decided this. Some hospitals, faced with difficulties funding ECRs, began to provide services themselves rather than using the nearest specialist centre producing disparity over expectations regarding improved choice and the actuality although some 'supraregional' centres of excellence were introduced.[95] Family Health Service Authorities controlled the allocation of money to non-fund-holding GPs.

The underlying philosophy was to encourage a climate in which it would eventually seem natural for privatisation of the NHS.[96] Patients gained 'rights'[97] without concomitant responsibilities.[98] The Charter was blamed for introducing imbalance in allocation of resources with 'time on waiting list' taking precedence over clinical need.[99] New complaints procedures were introduced[100] leading to an escalation in public discontent.[101] Controversially, managers were given more control over consultants in terms of appointment, job description and contract - evidence of growing distrust of professionalism. Miller points out that doctors finally had to recognise that their 'inefficient or unprofessionally irresponsible behaviour' could 'imperil the economic survival of their employing institution'.[102] Senior doctors had to justify treatment costs to hospital managers, many of whom had no healthcare background, resulting in tensions.[103] Doctors were expected to become more accountable for resource management. Their independence, guaranteed at the start of the NHS, was replaced by non-clinical regulation.[104]

In 1995-6, NHS expenditure reached nearly £41 billion ie. 16% of all public spending.[105] In 1996, the government said that the NHS should be available to anyone who wishes to use it; high-quality, applying the latest knowledge and the highest professional standards; available on the basis of clinical need, without regard for the patient's ability to pay and responsive to the needs and wishes of patients and carers.[106] The search for 'better and more efficient ways to meet the needs of patients must be relentless'.[107] Success would be judged

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[91]For instance, see the media debate over Child B (the ten-year old with leukaemia for whom the decision to refuse further treatment was initially expressed by the Health Authority as due to the costs involved and the need to fund care for others) and Rhys Daniels (whose bone marrow transplant was cancelled due to the closure of the unit treating him) and also the debate over Taxol for breast cancer patients. See discussion in Chapter 8.

[92]Klein R. Why Britain is Reorganizing its National Health Service - Yet Again. *Health Affairs* 1998;**17**,4:111-125 at p117.

[93]Mulholland & McAllister, op cit n72 at p26.

[94]Klein et al, op cit n60 at p81.

[95]Mulholland G, McAllister D op cit n72, at p26.

[96]Jacob JM. Lawyers go to hospital *Public Law* 1991, 255-281, 260-1.

[97]Via a Patients' Charter introduced in 1992 as part of the reforms under the 1990 Act (*The Patients' Charter and You: A Charter for England* 1991 (revised 1995) Dept.of Health, Wetherby). See also: Dyke G. *The New NHS Charter - A Different Approach* November 1998 Department of Health, Wetherby.

[98]This is being addressed with the introduction of a Zero Tolerance approach towards violent attacks on healthcare staff: Department of Health. *We don't have to take this: Resource Pack.* L20/002 November 1999 DoH, Wetherby.

[99]Royce RG. Observations on the NHS internal market: will the dodo get the last laugh? *BMJ* 1995;**311**:431-3 at p432.

[100]Introduced in 1988 under the Hospital Complaints Act 1985. The initial procedure was modified later: NHSE. *Complaints, Listening...Acting Improving: Guidance on Implementation of the NHS Complaints Procedure.* March 1996 NHS Executive, Leeds. This followed criticisms in the Wilson Committee Report (*Being Heard* 1994 Dept.of Health, London) and the government response in 1995 (*Government Response to Review of NHS Complaints Procedures Incorporating Acting on Complaints* EL(95)37 Dept.of Health, London).

[101]For a commentary on the effect of the Patients' Charter and the encouragement of a complaints culture see Bruggen P. *Who Cares? True stories of the NHS reforms.* 1997 Jon Carpenter Publishing , Charlbury, in particular pp132-133, pp142-3, 176-191.

[102]Miller F. Competition Law and Anticompetitive Professional Behaviour. *Mod.Law Review* 1992;**55,4**:453-481 at p462.

[103]Ibid.

[104]Hughes D op cit n43, at p99.

[105]O'Hara SP. The NHS - Past, present and future. *Biomedical Scientist* 1996:605-7. According to the Dept of Health publication *On the State of the Public Health* 1995 (HMSO, London at p19) the resident population of England was 48.9 million.

[106]Secretary of State for Health. *The National Health Service: A Service with Ambitions* (Cm 3425) The Stationery Office Ltd, London at pp4-5.

[107]Ibid, at p5.

under the headings of equity, efficiency and responsiveness with a strong focus on primary care.[108] Government measures to encourage self-sufficiency resulted in a 'two-tier' healthcare system[109] despite efforts to prevent this.[110] The quasi-market generated 'powerful forces creating inequality of access'.[111] The Major reforms concentrated more on effectiveness than fairness.[112] Medical audit was positively encouraged,[113] a process the present government is reinforcing. Technology began to be introduced to disseminate information.[114] Priorities within the acute sector focused on reducing waiting times with increased use of day beds for elective surgery. National and international trends encouraged greater social responsibility in healthcare.[115] The internal market helped to distance the government from blame as rationing decisions and waiting lists could be represented as reflecting local priorities or poor business management. A danger was identified that 'today's healthcare managers find themselves drifting between idealism and pragmatism, outwardly committed to a human service ideal yet conditioned by a survival mentality to favour the bottom line of financial well-being'.[116] As Wall objects, people without clinical qualification or professional/statutory codes of conduct to guide them were making resource allocation decisions.[117] Market economists are suspicious of the public service ethos yet the market economy depended upon the altruism of the voluntary sector to fill in the gaps in state provision.[118] The public became increasingly critical.[119] Legal challenges against refusal of funding for treatment were highlighted alongside stories of 'postcode' rationing in the media.[120] It became clear that the market economy in health was failing.[121]

2.3 Reforming the Reforms

The change in government in May 1997 led to an immediate announcement of the ending of the internal market[122] and an avowal to reintroduce the forgotten principle of equity in outcome which universality of access does not ensure.[123] Ham rightly predicted that, like the New Zealand healthcare reforms which abolished

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[108]*Department of Health. On the State of the Public's Health.* 1995 HMSO, London at p130. See also, NHS Executive. *Priorities and Planning Guidance for the NHS: 1997/98.* June 1996 Dept. of Health, Leeds. Total spend on primary care in 1996-97 was around £12.45 billion and represented 36% of the total revenue of the NHS: Department of Health. *Primary Care: Delivering The Future.* December 1996 HMSO, London.

[109]Kammerling R, Kinnear A: The extent of the two tier service for fundholders. *BMJ* 1996;**312**:1399-1401. Contra: Klein R. Why Britain is Reorganizing its National Health Service - Yet Again. *Health Affairs* 1998;17,4:111-125 at p118.

[110]Cutler T, Waine B. The politics of quasi-markets. *Critical Social Policy* 1997;**17,**2:3-26 at p9.

[111]Ibid, at p20.

[112]Milburn A. For a healthier Britain. *Fabian Review* 1997;**109,**3:22.

[113]GPs were given prescribing, analysis and cost data enabling them to monitor drug expenditure. The development of diagnostic methods suitable for use by GPs or nurses meant less emphasis on hospitals for diagnosis thus changing the shape of primary care in the future.

[114]In 1995, the NHS superhighway was launched which means that patient's files can be transferred across the country in seconds facilitating referrals and the obtaining of second opinions. Similar technology is used for fast delivery of laboratory results to GPs and wards.

[115]Catford J. *Public health - past, present and future.* The NHS Handbook. 10th Edn. JMH Publishing, London. 1995. See also: Jacob JM. Lawyers go to hospital *Public Law* 1991, 255-281 at p258 and Department of Health. *The Health of the Nation.* 1992 HMSO, London.

[116]Levey R, Hill M. Between Survival and Social Responsibility: in search of an ethical balance. *J.Health Administration Education* Spring 1986; 225-231 at p230.

[117]Wall A. *Ethics and the Health Services Manager.* 1989 King Edward's Fund for London, London.

[118]Ham C. Contestability: a middle path for healthcare. *BMJ* 1996; **312:**70-71.

[119]For a description of some of the media stories see: Klein et al, op cit n60 at pp78-82.

[120]For instance, one of the most contentious forms of inequality is the provison of in-vitro fertilisation therapy. *Woman's Weekly* 11 June 1996 reported that Dudley HA funds 70 IVF cycles per year and North Birmingham funds 60-70 yet just down the road South Birmingham and Solihull HAs fund no IVF treatment. Moving a couple of miles can make the difference between having to pay or not. See also: Rationing by Postcode. *Health Which?* June 1999 pp14-17 which reports which health authorities fund IVF, Beta interferon for multiple sclerosis, cochlear implants and reversal of sterilisation. Also: Anon. IVF 'rationed by postcodes'. *Health Manager Today* April/May 1999.

[121]Ham C. Contestability: a middle path for healthcare. *BMJ* 1996; **312:**70-71.

[122]A letter was sent by the incoming Labour administration to all Chief Executives of HAs, NHS Trusts and GPs announcing the end of the internal market. NHS Executive *Changing the Internal Market* EL(97)33. 22 May 1997. The Dept. of Health announced the End of the 'two-tier' system: Dept. of Health. Fairness and Equity for Hospital Treatment. DOH 97/169. 16 July 1997. Ham C. Reforming the New Zealand health reforms. *BMJ* 1997;**314,**1844-5.

[123]For a description of evolutionary reforms in healthcare systems see Abel-Smith B. *A review of Healthcare systems in seventeen OECD countries* 1994 OECD, Paris at pp15-27.

competition, there would be a similar emphasis on primary care and health outcomes.[124] However, NHS reform measures are consistently grounded in politico-economic considerations and lack the identification, and analysis, of ethical issues that can be provided by specialist advisors.[125] Whichever political group holds power, decisions still have to be made about how much money the state can safely remove from its citizens before rebellion occurs, and then how that money should be spent.[126] More money is being put into the NHS[127] but despite predictions in 1997, a 'health tax' to fund the NHS has not been introduced.[128] Such a tax had been considered prior to the 1990 reforms[129] but they can 'stifle growth in times of economic recession; reduce government's budgetary flexibility (and/or) raise questions of accountability, if an independent body decides how much tax to raise'.[130] Instead, the focus is on educating the public about the costs of ill-health to individuals and to society.[131]

Initial plans, aiming to 'build on' what the 1990 reforms had achieved,[132] were revealed in *The new NHS: Modern Dependable*.[133] The main stated aim is to improve quality thereby reducing 'unfairness'.[134] The move from 'secondary care' to primary care was not universally welcomed but is being developed further by this administration.[135] Greater control over professionals and the standards of care they provide is sought via the introduction of 'clinical governance'[136] a concept whose meaning is only gradually becoming clear.[137] This will end their nineteenth-century 'autonomy from both executive and legislative power'.[138] New disciplinary bodies are scheduled to be introduced possibly because of concerns over self-policing.[139]

The Acheson Report confirmed that inequalities in health were still rife.[140] *Saving Lives* then set out a 'third way'[141] with two key aims for the NHS as part of an overall strategy encompassing housing, environmental and

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[124]Ham C. Reforming the New Zealand health reforms. *BMJ* 1997;**314**,1844-5.
[125]Wall A. Best Behaviour. *Health Service J: Health Management Guide* May 1995 at pp3-7.
[126]Kaletsky A. Has the Chancellor got his priorities right this time? The Times 10 March 1999.
[127]Department of Health *Saving Lives: Our Healthier Nation.* (Cm 4386) July 1999 The Stationery Office, London.
[128]Grice A. Brown plans health tax to aid NHS. Sunday Times 29 June 1997.
[129]Baggott R, *Health and Healthcare in Britain.* 1994 McMillan Press Ltd, Basingstoke at pp175-6.
[130]Donaldson C. Why a National Health Service? The Economic Rationale. 1998 IPPR, London at p6.
[131]*Saving Lives: Our Healthier Nation* op cit n127, Chapter 2. The individual costs are represented as years of life lost; years of health lost and health disadvantage.
[132]Abel-Smith B, Glennester H. Labour and the Tory health reforms. *Fabian Review* 1995, **107**,3:2-4 at p3. The programme of reforms is designed to take place over a ten year period indicating a belief that the present government will be reelected at the next general election. Secretary of State for Health. *A First Class Service: Quality in the NHS* (1 July 1998) The Stationery Office, London.
[133]Secretary of State for Health. *The new NHS: Modern Dependable* (Cm 3807) December 1997 The Stationery Office, London.
[134]Ibid, at para 3.2. Also cited: *A First Class Service* op cit n132, at p4.
[135]Fulop NJ. Does the National Health Service want hospital-at-home? *J.Royal Soc.Medicine* 1997; **90**:212-215.
[136]*A First Class Service* op cit n132, at para 3.3. There is a concurrent emphasis on 'life-long learning' which aims to avoid the situation of professionals not bothering to keep up-to-date with new developments resulting in poor quality care being provided by some (para 3.28).
[137]The explanation given by the NHS Executive (HSC 1998/228:LAC(98)32: *The New NHS Modern Dependable* NHSE, Leeds at para. 20) was that it encompassed ten points: Quality improvement processes (clinical audit); quality organisation; clinical team leadership; evidence-based practice; evaluated practice and ideas; clinical risk reduction; identification of adverse events; patient feedback; identification of poor clinical performance; monitoring of clinical care and continuing professional development. This has many similarities with the 1990 reforms which emphasised compulsory participation in medical audit and new contracts setting out more clearly the duties and responsibilities of doctors (in addition to the more controversial resource management responsibilities). Control by managers will be replaced by control by scientists.
[138]Kelly M, Glover I. In search of health and efficiency: the NHS 1948 - 1994. In Leopold J et al (Eds) *Beyond Reason? The National Health Service and the Limits of Management.* 1996 Stirling Management Series, Avebury at p26. For a comment on the likely problems this will cause see: Klein R. Why Britain is Reorganizing its National Health Service - Yet Again. *Health Affairs* 1998;**17**,4:111-125, at p112.
[139]For example, the failure of the General Medical Council to strike off a doctor whose patient was starved to death and died weighing only 3 stone, 12 pounds: Horsnall M. Doctor tells why he gave order to starve patient. *The Times* 23 March 1999; Wilson E. GP in mercy killing case escapes being struck off. *Daily Mail* 27 March 1999. Another example of failure in self-policing can be seen in the decision by United Kingdom Central Council for Nurses not to proceed with disciplinary hearings against four nurses identified as having carried out abuses of patients over a three year period: Camden & Islington Community Health Services NHS Trust *Beech House Inquiry: Report of the internal inquiry relating to the mistreatment of patients residing at Beech House, St Pancras Hospital during the period March 1993 - April 1996.* Issued February 1999.
[140]Sir Donald Acheson. *Independent Inquiry into Inequalities in Health.* 1998 The Stationery Office, London, available on www.official-documents.co.uk. This showed little change from the Black Report findings: Sir Douglas Black. *Report of the Working Group on Inequalities in Health.* 1979 HMSO, London.
[141]The NHS Confederation. *The green papers for England and Scotland.* 1998 The NHS Confederation, Birmingham.

other areas to improve health.[142] First, 'to improve the health of the population as a whole by increasing the length of people's lives and the number of years people spend free from illness' and secondly, 'to improve the health of the worst off in society and to narrow the health gap'.[143] As Benzeval points out, 'the availability of social care services...can have an important impact on the abilities of health authorities to meet the needs of their populations'.[144] Government departments must identify the health implications of proposed developments.[145] Some commentators separate the healthcare system into two components: health[146] and sickness[147] but currently there is no clear distinction.[148] The government wants increased public involvement in identifying health need and greater input in terms of expert advice.[149] However, there is no evidence as to what course will be adopted when lay and professional input conflict. Shickle suggests that public preferences for healthcare indicate a 'willingness to pay for experimental, 'high-tech' life-saving treatments' at the expense of other treatments which would increase utility overall; a preference for treating the young or those with dependents at the expense of the old or those without dependents and a general willingness to discriminate on grounds of responsibility for own illness.[150] Running the NHS by ballot could produce as great a lottery regarding treatment availability as has existed in the past. The views of the most persuasive and vociferous will prevail. The predicted 'stakeholder' approach to healthcare has not been introduced[151] although this could reduce wasteful over-use of its resources.[152] Ten 'Health Action Zones', designed to develop frameworks for the NHS trusts and local authorities etc. to work together, were set up as pilots in 1998.[153] Non-acute healthcare purchasing could become the responsibility of local authorities.[154] The 'public contract model' is to be replaced by the 'public integrated model'.[155] Ending the increasing inequality in health is seen as vital[156] but 'postcode' rationing is still evident three years into the Labour administration.[157] The continuing philosophy, decried by some as a 'fallacy',[158] favours 'liberating humanity through providing health for all...using scientific rationality to solve problems of human morbidity and organizational inefficiency in the

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[142]*Saving Lives: Our Healthier Nation* op cit n127. In particular, see para 4.2.

[143]*Saving Lives: Our Healthier Nation* op cit n127, paras 1.23 & 3.10. The Stationery Office, London. Four areas, heart disease, cancer, mental health and accidental injury, will be targeted since there is great inequality across the country as to who suffers from them and what provision is made for treating them (para 3.10).

[144]Benzeval M et al. *Tackling Inequalities in Health: An Agenda for Action.* 1997 Kings Fund, London at p99.

[145]*Saving Lives: Our Healthier Nation* op cit n127, paras 4.45-4.47. Article 129 of The Maastricht Treaty, adopted in 1993 by the United Kingdom requires the impact upon health to be considered by governments when formulating policies. The present government has given positive reinforcement to this requirement by the appointment of a Public Health Minister.

[146]The WHO has defined 'health' as 'a state of complete physical, mental and social well-being'. World Health Organisation. *Constitution of the World Health Organisation.* Geneva: WHO 1946.

[147]Marmor T, in *Healthcare: Resources, Choices and Decisions St Catherine's Conference Report* op cit n58 at p15.

[148]The problems this creates can be seen in the conflict over whether Viagra should be freely available on the NHS with doctors using clinical judgement or whether impotence not related to diseases like diabetes and multiple sclerosis should be seen as a non-health issue outside the remit of state provision. Chisholm J. Viagra: a botched case for rationing. *BMJ* 1999;**318:**273-4.

[149]*Saving Lives* op cit n127, Chapter 3 - see particularly paras 3.22 & 3.40. See also: *A First Class Service* op cit n132, para 4.59. The first nationwide survey of 150,000 NHS patients and users views was announced in 1998: Dept. of Health. DOH 98/333, 12 August 1998. For a discussion of some of the difficulties involved in eliciting public participation in healthcare, see Donovan J, Coast J. Public Participation in Priority Setting: Commitment or Illusion? In Coast J, Donovan J, Frankel S (Eds) *Priority setting: the health care debate.* 1996 John Wiley & Sons Ltd, Chichester at pp203-234.

[150]Shickle D. Public preferences for healthcare: prioritisation in the United Kingdom. *Bioethics* 1997; **14,**3 & 4:277-290.

[151]Verity A. Revealed: Labour's plans for pensions. *The Sunday Times* 18 May 1997.

[152]Plender J.*A Stake in the Future: the Stakeholding Solution.* 1997 Nicholas Brealey Publishing, London. See also, Plender J: A stake of one's own. *Prospect* February 1997 at pp20-4.

[153]*Saving Lives: Our Healthier Nation* op cit n127, at para 3.51. The 'first wave' of these was to receive £4 million in 1998-9 and it was pledged that in 1999 £30 million would be given to Health Authorities to spend on joint initiatives with Local Authorities. The government intends to set up a second set of Health Action Zones in 1999.

[154]Paton C. Present dangers and future threats: some perverse incentives in the NHS reforms. *BMJ* 1995;**310:**1245-8, at pp1246-7.

[155]Abel-Smith B. *A review of Healthcare systems in seventeen OECD countries* 1994 OECD, Paris at pp45-51.

[156]Wise J. Britain has become less equal in death. *BMJ* 1997;**315**:384. Reporting the findings of the Rowntree Foundation. Joseph Rowntree Foundation. *Death in Britain: How Local Mortality Rates have Changed: 1950s to 1990s.* 1997 York Publishing Services, York (summary on www.jrf.org.uk).

[157]For example, the death rate from coronary heart disease is three times higher in Manchester than Kingston in Surrey. *Saving Lives: Our Healthier Nation* op cit n127, at para 2.9.

[158]Kelly M, Glover I. In search of health and efficiency: the NHS 1948 - 1994. In Leopold J et al (Eds) *Beyond Reason? The National Health Service and the Limits of Management.* 1996 Stirling Management Series, Avebury at p30.

NHS'.[159]

The Health Act 1999 ended the market economy and GP fundholding. The Lords was concerned at the presence of 'Henry VIII' clauses allowing the possibility of 'draconian' powers.[160] Feedback on the responses to the consultation paper[161] was only issued after the first reading of the Health Bill.[162] The prognosis for meaningful debate on healthcare provision seems uncertain. All GPs now belong to Primary Care Groups (PCGs) which are similar to the pre-existing GP commissioning groups.[163] Their responsibilities continue to be meeting 'national...health priorities and policy.'[164] It is envisaged that the PCGs will agree with 'secondary care providers' (ie. hospitals) what services are provided at primary, secondary and community level.[165] Little attention seems to have been paid to Benzeval's concerns regarding similar proposals in 1994 that, as health authorities 'withdraw from direct purchasing...interventions directed at communities and groups that are more disadvantaged will be significantly reduced'.[166] The PCGs will control 'prescribing, referral, discharge...based on clinical and cost effectiveness.'[167] Delays in the Health Bill reaching the statute book meant that both PCGs and GP Fundholders existed side-by-side for a time.[168] Ex-GP fundholders are finding PCGs frustrating because they require too much 'discussing issues' and have reintroduced queuing at the expense of meeting patient needs fast.[169] Although emphasis was placed on reducing administration costs, closing down fundholders was expensive[170] and concerns were raised that costs would increase by £300m pa.[171] Health Authorities who meet the national targets given in the Health Improvement Programmes will be rewarded financially[172] as will PCGs.[173] This continues the much-criticised policies of the previous administration. Discretion to fund treatments according to the purchaser's perception of 'local need' resulted in local discrimination but the aim now is local delivery according to 'national yardsticks'.[174] National Service Frameworks have been introduced as proposed in *A First Class Service* to 'set national standards' and targets for improvements in health.[175] However, government changes of mind remain problematic[176] since these Frameworks are dedicated to change.[177] Initially, four target areas were identified but, although work is in progress on heart disease and mental health, the work on cancer and accidental injury seems to have been

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[159]Leopold J et al (Eds) *Beyond Reason? The National Health Service and the Limits of Management.* 1996 Stirling Management Series, Avebury at pp5.

[160]Crail M. Lords tune into The Bill. *Health Service J.* 18 February 1999 pp9-11.

[161]*A First Class Service* op cit n132.

[162]Health Service Circular HSC 1999/033 NHS Executive, London, 19 February 2000.

[163]The order establishing Primary Care Groups was made 15 October 1998. National Health Service Act 1977: Directions by the Secretary of State As To The Establishment of Primary Care Groups by Health Authorities.

[164]*A First Class Service* op cit n132, at p29. See also: *Saving Lives: Our Healthier Nation* op cit n127.

[165]*The New NHS: Modern Dependable* op cit n133, at para.82 (ii). It has also been proposed that 'hotel' charges should be introduced for patients whose nursing care would still be funded by the NHS. Timmins reports that this was first proposed by the Labour Chancellor of the Exchequer, Hugh Gaitskell, in 1951: Timmins N. *NHS 50th Anniversary* op citn42, at p4.

[166]Benzeval M et al. *Tackling Inequalities in Health: An Agenda for Action.* 1997 Kings Fund, London at p101.

[167]Ibid.

[168]Anon. PCGs and fundholding will run in tandem following £19m legislation timing hitch. *Health Service J.* 4 February 1999 at pp4-5. Chris Ham considers that some doctors are reluctant to participate in PCGs since this could mean having to directly ration care to patients. Ham C. The next 10 years. *The Lancet* 1998;**352:**56-7.

[169]Lambden P. Remember the fun in fundholding. *The Health Summary* July/August 2000 at p25.

[170]Anon. What's in the Health Bill? *Health Service J.* 4 February 1999 at pp4-5.

[171]Crail M. Lords tune into The Bill. *Health Service J.* 18 February 1999 pp9-11.

[172]*Saving Lives: Our Healthier Nation* op cit n127.

[173]*The New NHS: Modern Dependable* op cit n133, at paras. 81 & 84 (c) and Annex 4A.

[174]*A First Class Service* op cit n132 at p7, para 1.14. Measured by the National Survey of Patient and User Experience: p10, para 1.17.

[175]*A First Class Service* op cit n132 at para 2.34. The initial four areas identified were: heart disease, cancer, mental health and accidental injury as indicated in *Saving Lives: Our Healthier Nation* op cit n127.

[176]Rotherham HA launched its five year health strategy in August 1993 based on the government White Paper, *The Health of the Nation* (1992 HMSO, London). However, its three aims of achieving health gain, making services people-centred and making effective use of resources had to be modified in 1996 when the government focus changed to having a 'primary care-led NHS'. Greagsby P et al. Life Preservers *Health Service J.* July 4 1996 pp28-29 at p29.

[177]*A First Class Service* op cit n132 paras 2.34 - 2.43.

displaced in favour of 'older people' and 'diabetes'.[178] Lack of continuity in government approach wastes resources. The focus in A First Class Service is on equity, efficiency and appropriateness[179] but in *Saving Lives* it is outcomes with little mention of improving access to healthcare.[180] This confusion over whether the goal is equity of outcome or equity of opportunity is problematic.[181] GPs have to place national health priorities before their perception of local needs. For example, government guidance requires suspected breast cancer cases to see a specialist within two weeks so the system is flooded with referrals, some of which are inappropriate, and the really urgent cases are not receiving treatment (as opposed to diagnosis) as fast as before.[182]

There are new quangos. The National Institute for Clinical Excellence (NICE)[183] will promote 'clinical and cost-effectiveness through guidance and audit' and 'advise on best practice in the use of existing treatment options, appraise new health interventions, and advise the NHS on how they can be implemented'.[184] The Commission for Health Improvement will 'improve clinical quality'.[185] The sub-text that what is/will be achievable is subject to resource availability is less overt: 'an emphasis on quality and the need for financial responsibility are not contradictory or incompatible aims'.[186] Restrictions on drug prices will be introduced.[187] This could mean it becomes uneconomical to licence some products for use in this country so effective treatments, available elsewhere, are withheld from British patients.[188] Pharmaceutical companies are also concerned that NICE will 'impact' on the 'uptake of effective new treatments'.[189] This is likely since there will be delays whilst NICE conducts evaluations. Since clinical effectiveness is not paramount, cost-effectiveness will still play a strong part in decisions by governmental agencies as to whether new treatments become available or not. If the cost to society is too high it may outweigh the cost to the individual in terms of receiving inferior treatment. There is evidence that some clinicians consider this trade-off acceptable and ethical even if the public do not.[190] It is questionable whether the focus of effectiveness will, or should, 'trump' ethical concerns about patients being denied treatment because their illness is lifestyle induced.[191] Therefore, it is unsurprising that the feedback on *A First Class Service* indicated concerns about 'the risks of raising public expectations to a level which services could not fulfill'[192] although the 'stronger national focus' and 'commitment to...consistency in quality of clinical care' were welcomed.[193] Claims like, 'it must be for the

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[178]Health Service Circular HSC 1999/033 19 February 2000 NHS Executive, London at p7, para 14.

[179]*A First Class Service* op cit n132, at p13, para 2.3. These principles are implicit rather than explicit in the text.

[180]*Saving Lives: Our Healthier Nation* op cit n127, Executive Summary.

[181]Hope J. Death sentence for our cancer patients. Daily Mail 1 July 2000.

[182]Rogers L. Doctors criticise failure of breast cancer reform. *The Sunday Times* 23 April 2000.

[183]NICE will cover only England and Wales. In Scotland, a similar organisation, to be introduced under the Scottish legislation, will be known as the Clinical Resource and Audit Group and the Clinical Standards Board.

[184]*A First Class Service* op cit n132, at para 2.6. The name and resultant acronym for this new body has similar 'symbolic connotations' to those identified in the use of 'the Trust' in 1991 by the Conservative administration by Hughes op cit n43, at p95.

[185]*A First Class Service* op cit n132, at para 4.4 (See also, Health Act 1999 ss 19-20 and Sch.2).

[186]See, for instance, para 3.2 *A First Class Service* op cit n132, para 3.2.

[187]Health Act 1999 ss33-38. The Secretary of State had the power, under the National Health Service Act 1977 s57, to control the prices of drugs prescibed for NHS patients, by setting a maximum limit, but this power was never exercised. Miller suggested, in 1992, that use of this power could replace the anti-competitive 'voluntary' agreements regarding drug pricing that have been a feature of British healthcare since *Medicaments Reference* [1971] AER 12: Miller F. Competition Law and Anticompetitive Professional Behaviour. *Mod.Law Review* 1992;**55**,4:453-481, at pp478-9.

[188]There are also proposals to curb GP spending on prescriptions which reach further than even the Conservative administration dared attempt. Fraser L. Blair's bitter pill for doctors. Mail on Sunday 9 November 1997. See: *The New NHS: Modern Dependable* op cit n133, paras. 32-34 and *A First Class Service* op cit n132, at paras 2.24 & 2.30.

[189]NHS Executive. *Health Service Circular* HSC 1999/033 1999 NHSE, Leeds at p6, para 8.

[190]Culyer AJ. Maximising the health of the whole community. *BMJ* 1997; **314**:667-9. See also: Dobson R. Brain cancer patients denied 'wonder drug'. *The Sunday Times* 30 April 2000.

[191]Shickle has pointed out that a majority of the public would preference treatment for non-smokers over smokers. Non-treatment of smoking related heart disease has been justified on the grounds that it would be ineffective due to continued smoking. Shickle D. Public preferences for healthcare: prioritisation in the United Kingdom. *Bioethics* 1997; **14**,3 & 4:277-290, at p288.

[192]HSC 1999/033 op cit n189, at page 5, para 5.

[193]Ibid, at page 5, para 3.

individual clinician to decide what is in the best interest of the individual patient. Each patient is different and treatment must be tailor-made to their specific needs'[194] will be seized upon despite the cautionary note that 'NICE will produce clear guidelines for clinicians about which treatments work best for which patients...(and)...assess new drugs, treatments and devices for their clinical and cost-effectiveness'.[195] Harris suggests that 'it is a fallacy to suppose that the measure of what is best for the individual patient or condition can also be the measure of the most efficient or best way of distributing resources...when this amounts to prioritising patients for treatment rather than treatments for patients'.[196] The independence of clinicians to choose how to treat their patients seems increasingly threatened.

2.4 The NHS Plan

The 'National Survey of Patient and User Experience', designed to elicit the views of local people on the services they receive and require, raised more concerns than any other proposal.[197] Such surveys, used well, could yield important information but, used cynically by a government looking for re-election, are likely to produce placatory measures only. Levitt and Wall suggest that 'governments are there to satisfy the electors rather than change society' and doubt that any government will act in a way that truly reduces inequality in health.[198] A long-term strategy for the NHS was outlined following a badly designed 'survey' of public opinion.[199] A lack of design robustness means opinions elicited will have little value.[200] A set of core principles have been committed to. Universal access on the basis of clinical need will be maintained.[201] The 'consumer's only right is to have access to the healthcare system: once that has been achieved, it is for the professional providers to determine what treatment is appropriate'[202] Scope is present to redefine 'clinical need'. Currently, it is doctor-determined. It could become increasingly politically-determined. A comprehensive range of services will be provided where 'clinically appropriate (and) cost effective'.[203] Services will be centred around 'the needs and preferences of individual patients, their families and their carers'.[204] However, this statement is misleading. There is an unacknowledged tension inherent in allowing 'citizens' to have a say in what services will be provided to meet patient needs.[205] Patients may believe that services will be more

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[194] *A First Class Service* op cit n132, at para 1.11.

[195] Ibid, at para 1.15.

[196] Harris J. The case against: what the principle objective of the NHS should really be. *BMJ* 1997;**314:**669-672,670.

[197] *A First Class Service* op cit n132, at para 4.59 and HSC 1999/033 op cit n189, pp11-12, paras 32-34. However, Edgar indicates that the input of mass media can actually be more important than formal state consultation procedures which 'serve to stifle the spontaneity for public disagreement and concern'. Edgar A. Healthcare Allocation, Public Consultation and the Concept of 'Health. *Healthcare Analysis* 1998;**6:**193-8 at p198.

[198] Levitt R, Wall A op cit n17 at p282.

[199] Department of Health. *The NHS Plan: A plan for investment, a plan for reform.* (Cm 4818-1) 2000 The Stationery Office, London. Available on www.nhs.uk/nhsplan accessed 7 August 2000, Preface.

[200] The recent Department of Health consultation exercise 'Have your say on a better NHS' conducted on in June 2000 can be criticised for its lack of research robustness. There were delays over sending out the printed leaflets which meant the date by which responses were to be received (5 June 2000) had to be changed. The leaflets only appear to have been produced in standard, written, English which meant that many users of the NHS (for example, ethnic minorities; people with poor literacy skills; sight-impaired and learning disabled) were excluded from the consultation exercise.

[201] Ibid, principle 1.

[202] Klein R: *The New Politics of the NHS.* 1995 Longman, London at p232.

[203] *The NHS Plan* op cit n199, Preface, principle 2.

[204] Ibid, principle 3.

[205] Ibid.

individualised because they fail to realise that the investment to achieve this will not be forthcoming so choices will continue to be made. Discrimination will be challenged.[206] The needs of different populations will be met[207] but these cannot be clearly known since the survey failed to reach many of these 'different populations'.[208] Regional inequalities will continue even though RAWP will be reviewed again.[209] Devolution to the regions will be on the basis of 'earned autonomy' but Halpern points out that the reality of the Plan is to increase centralisation.[210] He concludes that there is 'little real understanding' of health inequalities shown.[211] *Improving Health in Wales* reveals how un-national the NHS is likely to be in the future.[212] There will be 'a new pluralism in NHS policy making'.[213] Community Health Councils (CHCs), which have provided 'coherent and well-documented criticism', are being abolished in England in favour of more politically-controlled scrutineering by Patients' Fora and Patients' Advocates (PALS) which will lack the independence and statutory powers of the CHCs.[214] However, CHCs will continue to exist in Wales alongside PALS.[215] Health Authorities will be abolished in Wales producing a flatter structure with Local Health Groups 'tackling health inequalities and the wider issues that impact on people's health - such as housing, education and economic development'.[216] There will be more free prescriptions, dental care and eye-tests in Wales.[217]

New ways to address funding inequalities in primary care will be investigated.[218] The NHS Performance Assessment Framework will measure improvements in access to services for black and ethnic minority groups.[219] There is no guarantee that the necessary funding for an effective alternative to RAWP will be found. Improvement in service quality and reductions in negligent errors will be sought.[220] Much of the extra money allocated in the March 2000 budget to the NHS is liable to be lost in meeting medical negligence claims.[221] The NHS will support and value its staff but the reality is that many staff feel undervalued and demoralised.[222] The pressure to continue training and personal development[223], the threat of litigation, and an increasingly controlling attitude from central government with the introduction of 'nationally agreed policies and

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[206]Ibid.
[207]Ibid, principle 4.
[208]THS. Commentary on the NHS Plan. *The Health Summary* July/August 2000 at p13.
[209]*The NHS Plan* op cit n199, Chapter 13, para 13.9.
[210]Halpern S. The NHS Plan: A plan for investment, a plan for reform: Kids get an apple a day... *Br.J.Health Care Management* 2000;6,8:349-350 at p349.
[211]Ibid, at p350.
[212]National Assembly for Wales. *Improving Health in Wales: A Plan for the NHS with its partners*. January 2001 National Assembly for Wales, Cardiff.
[213]Ibid, at p4. As part of this, Professor Peter Townsend is carrying out a 'major resource allocation review' for the National Assembly (loc cit).
[214]Health and Social Care Bill, (Session 2000-2001) introduced to the House of Commons 20 December 2000, cll.11-16. See also, BMA. Press Release: General Practitioners' Response to the Health and Social Care Bill. 21 December 2000 British Medical Association, London; THS. Hear no evil, See no evil, Speak no evil. *The Health Summary* January 2001 pp1-4; British Medical Association Press Release: BMA warns that patient consent and confidentiality are threatened by the Health and Social Care Bill. 7 February 2001 British Medical Association, London (see cl62(3) and (4)of the Bill) and Association of Community Health Councils. *Watchdog or Lapdog?* November 2000 ACHCEW, London (www.achcew.org.uk). It is worth noting that the CHC gave a well-considered submission to the Bristol Inquiry: www.bristol-inquiry.org.
[215]National Assembly for Wales, op cit n213 at p38.
[216]Ibid, at p10. See also, pp74-75.
[217]Ibid, at pp12-14.
[218]*The NHS Plan* op cit n199, Chapter 13, para 13.10.
[219]Ibid, Chapter 13, para 13.13.
[220]Ibid, principle 5.
[221]The escalation in medical negligence litigation was predicted in 1991: Jacob JM op cit n95, at p265.
[222]Bruggen P. *Who Cares? True stories of the NHS reforms.* 1997 Jon Carpenter, Charlbury, at p14. See also some of the consultant's comments in this thesis. See also: Webster et al. Doctors challenge NHS Plan. *The Times* 28 July 2000 and comments made by Tony Blair, which suggested that much of what is wrong with the NHS is the fault of doctors: Miles, A. Can the NHS be Saved?: Last Chance *The Times* 26 May 2000.
[223]*The NHS Plan* op cit n199, principle 6.

standards'[224] are likely to do little to address this. For instance, targets on tackling heart disease require that ambulance response times are shortened.[225] Patients may sue the ambulance service for slow response.[226]

The NHS will not 'subsidise individuals' privately funded healthcare'.[227] This is an important step that may enable hospitals to recover the costs of medical treatment where the patient was initially treated privately but post-operatively the patient required intensive care treatment which the private sector could not provide. Partnerships in care will be sought 'to ensure a seamless service for patients'.[228] The political separation of health and social services will not be addressed despite 'the longest unrequited courtship since the last Doris Day movie'.[229] Duplication of personnel, equipment and inevitable delays in identifying patient need and delivering appropriate care will continue. The needs of the elderly are clearly delineated.[230] Similar principles would be appropriate for other disadvantaged groups such as the mentally ill, learning or physically disabled. The goal is to keep the elderly out of hospital and as independent as possible.[231] Whilst this is what many want, it could have a detrimental long-term effect of making the elderly seem less entitled to hospital treatment.

Effort will be focused on health promotion measures.[232] Health Improvement Programmes[233] are being introduced alongside Health Action Zones.[234] Individual responsibility for health is being encouraged which means that individual blame can follow. The clinical priorities will be cancer, heart disease and mental health.[235] The 'new technologies', particularly the 'new genetics' will be developed 'in the interests of society' as a whole.[236] Currently, the main role of the new genetics is to identify those at risk, particularly foetuses, of developing certain conditions. Pressure will be placed upon individuals to undergo abortion rather than have a disabled child.[237] Patients will have responsibility to minimise risks, including those to which their genes make them vulnerable.[238] 'Blame' will become increasingly prevalent within an ill-informed society.[239] Any encouraging of a 'blame culture' seems short-sighted given the damage it has done through the rise in medical litigation. Doctors may demand, through the courts, that screening tests are carried out on children in order to start treatment.[240] The potential for a genetics underclass to develop is present particularly given that the government has, unlike any other government worldwide, authorised the use of gene tests by insurance companies.[241]

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[224]Ibid.
[225]Ibid, Chapter 14, para 14.21.
[226]For example, *Kent v (1) Dr Yvonne Griffiths (2) Dr Marian Roberts (3) The London Ambulance Service* [2000] 2 WLR 1158.
[227]*The NHS Plan* op cit n199, principle 7.
[228]Ibid, principle 8.
[229]Halpern S op cit n210 at p349.
[230]*The NHS Plan* op cit n199, Chapter 15, para 15.7.
[231]Ibid, Chapter 15, para 15.14.
[232]Ibid, principle 9.
[233]*Saving Lives: Our Healthier Nation* op cit n127, para 10.18.
[234]Ibid, at para 10.23.
[235]*The NHS Plan* op cit n199, principle 6, Chapter 14, para 14.1.
[236]Ibid, principle 10.
[237]See: *Saving Lives: Our Healthier Nation* op cit n127, para9.26. Rogers L. Having disabled babies will be 'sin', says scientist. *The Sunday Times* 4 July 1999.
[238]*The NHS Plan* op cit n199, Chapter 1, para 1.4.
[239]Cedar S, Terry L. Genes and Genealogy. *Family Law* 2000;**30**:744-747, at p745.
[240]Ibid, at p746.
[241]Mayor S. UK allows insurers to use gene test for Huntingdon's disease. *BMJ* 2000;**321**:977. See also: www.doh.gov.uk/genetics/gaic.htm.

More consultant posts are planned particularly in order to improve oncology services but the achievability of this is doubted.[242] Changes are proposed to prevent consultants taking on private work to the detriment of the NHS.[243] These are opposed by junior doctors.[244] More doctors and nurses are working in the NHS than in 1997 but it is unclear whether total hours have increased.[245] Lack of staff cover, or appropriately qualified staff, means treatment may be withheld.[246] Patients will be encouraged to complain more about their local services because their views will help decide the level of funding.[247] This can only lead to further demoralisation. Waiting lists have continued rising thereby denying some patients necessary and appropriate care[248] so the NHS will start to use private hospital facilities in a new 'concordat'.[249] The disparity between facilities in the NHS and what is achievable within the private sector will become more apparent. This could encourage the public to consider whether the NHS model of healthcare should be rejected in favour of alternative provision. Ironically, Labour could achieve the attitude change the Conservatives sought, but failed, to introduce.

2.5 Perceptions of the Problems

There is a strong public feeling that inequality in healthcare provision exists and that the lowest socio-economic groups have the worst health as the Black Report suggested.[250] Not all welcome devolution and believe it may exacerbate problems.[251] The Adults with Incapacity (Scotland) Act 2000 is nearly in force but the English equivalent has been postponed until after the election. It seems that disparity of treatment for the mentally and physically disabled is condoned.[252] The adoption of a 'minimal welfare state' principle during the Conservative administration has left its mark.[253] Whether there should be an NHS is being questioned.[254] Variable approaches to decision-making lead to conflict and accusations of arbitrariness or unfairness. Cases like Child B suggest that resource allocation is a significant cause of conflict.[255] Cases like *Bland*[256] and *Glass*[257] indicate that quality of life interpretations lead to conflict. As Klein et al point out, 'despite all the changes in the structure of the NHS, decisions about which patients should be treated, when and how, remain the prerogative

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[242]Ferriman A. Doctors doubt whether cancer targets can be met. *BMJ* 2000;**321**:850.
[243]*The NHS Plan* op cit n199, Summary.
[244]Rufford, N. Hundreds of surgeons plan to quit NHS in contract row. *The Sunday Times* 26 November 2000.
[245]*The NHS Plan* op cit n199, Chapter 1, para 1.25.
[246]The Commission for Health Improvement has criticised the replacement of experienced staff with cheaper, less experienced nurses within the NHS: Commission for Health Improvement. *Investigation into Carmarthenshire NHS Trust.* November 2000, available on www.doh.gov.uk/chi/index.htm.
[247]*The NHS Plan* op cit n199, Summary.
[248]Warden J. Hospital waiting lists grow by 13% in England. *BMJ* 1997;**315:**501. At 31 August 1998, 65,200 English residents had waited over 12 months for NHS treatment. *Hansard* 22.10.98 col 1180.
[249]The use of this word is strongly criticised by Cowper: Cowper A (Editor). Managing The NHS Plan for Investment and Reform. *Br.J.Health Care Management* 2000;**6**,8:347-8 at p347.
[250]Sir Douglas Black (Chair). *Report of the Working Group on Inequalities in Health.* 1979 HMSO, London. See also: Black D: *Inequalities in Health: The Black Report.* 1982 Penguin, Harmondsworth and NHSE. *Standards of Excellence: Healthcare delivery in the European Community.* 1993 NHS Training Directorate, Leeds.
[251]Warden J. NHS devolved to Scotland and Wales. *BMJ* 1997;**315**:273.
[252]Edgar A. Healthcare Allocation, Public Consultation and the Concept of 'Health'. *Healthcare Analysis* 1998;**6:**193-8 at p195.
[253]Davy B, Popay J (Eds). *Dilemmas in Healthcare.* 1993 Open University Press at p30.
[254]Donaldson C. *Why a National Health Service? The Economic Rationale.* 1998 IPPR, London.
[255]*R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.
[256]*Airedale NHS Trust v Bland* [1993] AC 789.
[257]*R v Portsmouth Hospitals NHS Trust ex parte Glass* [1999] 2 FLR 905.

of the health care professions'[258] although the strength of public concern has led to attempts to pass protective legislation.[259] Therefore, whilst appropriateness of treatment obviously encompasses economic, medical and ethical considerations, it is important to identify what doctors, themselves, consider to be the main difficulties when making decisions.

2.5.1 Empirical Research Analysis

In order to discover the extent to which medical decisions were challengeable, possibly through the courts, the eighty-five consultants were asked the following questions:

Do you have any input into how resources are allocated? Have you had to restrict the medical treatment or tests available to certain patients as a result of limited resources? If so, have you used QALYS?

Have you ever had conflict with the patient, their relatives or other members of the hospital team over a decision to treat or not to treat a patient? If so, how was it resolved?

What has been the hardest decision to treat or not to treat a patient that you have ever been involved in? What principles guided you?

Many of the consultants minimised the number of instances of conflict. The initial response was to deny experiencing conflict then most related various instances of conflict with fellow professionals, patients or, most commonly, relatives. The effect of resource allocation upon the decision-making process varied considerably with some consultants reporting no significant restrictions upon resources and others feeling lack of resources was a major source of problems. Some consultants, when asked to describe their most difficult decision, described situations where there was potential for conflict, or even decisions where it would have been proper to have applied to court first. Respecting patient autonomy and good communication seemed crucial to avoiding conflict or preventing complaints or litigation.

2.5.1.1 The Impact of Limited Resources

Only twenty-two had direct input into resource allocation decisions by the purchasers or input within their own hospital regarding global allocation of resources.[260] Several felt alienated by the disregard for their input, one passionately:

I have the status of a floor cleaner! A23

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[258]Klein et al, op cit n60 at p83.
[259]For example, in the 1999-2000 session, the Medical Treatment (Prevention of Euthanasia) Bill was introduced to the House of Commons without success.
[260]There were 4 Medical Directors; 6 Clinical Directors; 2 Surgical Directors; 1 Chair & 1 Senior member of the Renal Management Team; 1 member of Paediatric Advisory Committee; 1 Chair of Neurosurgery; 1 member of Paediatric Directorate; 1 Lead Physician; 1 member of the Urology Board; 1 member of Psychiatric Advisory Committee; 1 member of Surgical Board; 1 member of Ophthalmology Board.

Fighting for resources was a source of major frustration for the majority of consultants regardless of how they rated their input:

> *One has to make a case for developments as they arise and for updating existing procedures and treatments. It is always a battle.* C15

> *We run a management team **versus** the managers' team on how to use resources... My role is to lead that team.* A21 (his emphasis)

> *We get allocated resources based on last year's activity...you get between 3-7% less resources the next year to provide the same service. This is in a specialty...where probably you need a 20 % increase just to keep up with technological advances.* B15

> *We're allowed to voice opinions although I don't think those opinions have a major effect on the budget.* C10

The majority had restricted treatment offered to patients because of inadequate, or poorly managed, resources sometimes when the proposed intervention was a minuscule proportion of the cost of care of the patient. Different ways of restricting treatment were evident:

> *Yes...we're overspent.* D3

> *Delaying admission is a way of restricting treatment.* C3

> *Arbitrary and implicit...(rationing's).occurred by the back door.* C4

> *The pharmacy would only prescribe me two doses of it. This stuff is £7.00 an ampoule...there are some people that are always sick after anaesthetic and it stops this.* D6

> *The Patients' Charter...everybody has to be treated within a certain time.* B19

Some had withheld treatment but not withdrawn treatment once begun. Sometimes the separation of budgets between care providers meant treatment was withheld because one refused to fund continued treatment:

> *There was an issue involving the cost of drugs for HIV (starting treatment)...(but)...I've never had to withdraw treatment.* A35

> *If I want to put a patient on such a drug*[261] *I have to ask the GP if they are going to prescribe it long-*

[261]He quoted one that he uses for Parkinson's disease as costing £8,000 pa per patient.

term once I have stabilised the patient. If they won't I effectively have to deny that patient the treatment. D9

Eleven felt their practice had not yet been affected:

We have cut every corner there is to still maintain treatment levels...the price is there are no more cuts left. B15

I don't think money's the problem in the health service. D2

None was satisfied with the current model of resource allocation because it was poorly-managed and not patient-centred:

The health authority...will allocate resources on the basis of mortality figures and waiting lists...it doesn't look at quality of life. A33

The concept of money following the patients doesn't actually materialise. D13

We tend to get important operations...or where they have been messed about in the past...or people who've made arrangements for their dog to go into the kennels. D8

The thing that really causes problems...is fundholding and contracting and all that purchaser-provider business where there was competition between the trusts. D2

Several consultants expressed concerns that the current system was unethical, one because there was no system for facilitating rapid discharge once they were fit for discharge:

If a patient is fit they should go home...On average, patients stay in hospital two days longer than necessary simply because arrangements have not been made for them to go home. A23

Others felt the system was unjust:

I don't want different criteria applied in different parts of the country so I think that some drug or resource rationing has to become part of our culture. A1

It shouldn't be different in one district from another. C9

*I feel most uncomfortable about decisions about what is provided occurring as a result of where you happen to be, **which month** are we in...The rationing of care according to the fact that this area has used its **quota** for a particular treatment I find completely untenable and the rationing of care*

*according to the **budget allocation** is at least as unethical, if not more so, particularly when it comes to children.* C14 (his emphasis)

QALYs were rarely used. This lack of use could be due to professional suspicion, ethical concerns, lack of direction from local purchasers or lack of sufficient concrete information to make them usable.

We are not using QALYs at the moment though that may be forced on us in relation to cancerous disease. B6

I know what they are but I have never used them. C1

We don't use QALYs. D13

QALYs are anti-elderly. B18

QALYs are very badly flawed. They usually have no capacity to look at multiple diagnoses. A22

Only three admitted using them. This was solely to justify treatments which otherwise would not be funded:

I tend to use QALYs in the context of feeling I can support certain types of treatment...on children...but I don't formalise it. C2

If we want a new drug for prevention of kidney transplant rejection one of the grounds on which we have to justify our desire to use that drug is on a cost per QALY analysis. A15

We have, in one area, used QALYs to try to argue a case.[262] C6

There was evidently much dissatisfaction with the current model. The almost total rejection of QALYs except where they could be used for patient advantage indicates that there is a formidable division between healthcare managers and doctors over resource allocation. One concentrates on provision for all, the other on individuals. Only if a model overcoming this division can be found can healthcare allocation be improved.

2.5.1.2 Patient-centred Considerations

2.5.1.2.1 The patient's 'best interests'

Decisions were made using best interests and/or autonomy but only one consultant spoke of consciously employing principled reasoning:

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[262]The case they were trying to make to the local Health Authority was in favour of a particular chemotherapy treatment for ovarian cancer where another Health Authority had carried out detailed QALY assessment and approved its use.

Sometimes I'm a bit slower doing in withdrawing treatment than they would wish...It's because I've got to do this consistently, and properly, and using the principles, and only when it is the right time by my judgement. I have to do it the same way every time. A6

There was recognition that not all doctors act in the patient's best interests:

Doctors may fail to take proper account of the patient's best interests sometimes: Doctors...will do things because it is possible. They over-treat and they don't take a commonsense view of it and say is it actually going to be of benefit. D7[263]

Conflict with relatives arose over identifying 'best interests':

I've had conflicts often with relatives over how to manage their relative. D5

The parents didn't want to continue treatment...the medical team felt it was not appropriate to stop...premature baby who had some complications...the family already had one handicapped child...the father had muscular dystrophy...it was more than they could cope with...Eventually he was taken into care. A7

If we are all acting in the patient's best interest then there is no actual conflict of interest - it's just a case of deciding what is the patient's best interest. D7

Some consultants would prioritise the patient's needs over the relatives:

Although I'm meant to be bound to the patient I also have a wider perception of the needs of the family but if there is a conflict, I would always have to side with the patient. B1

In other cases, pacifying relatives sometimes trumped patient best interests:

I was asked to do a tracheostomy...it was not an appropriate use of resources... if we had not...the family would never have been happy...if you simply had the interests of the patient, we probably should not have done it...but the family was depending on him as a focus.[264] D8

An 18 year old boy...was brain dead but his lovely mother wouldn't believe it. I obtained an EEG[265]*...which showed a complete lack of brain activity which convinced her and she allowed me to stop ventilation.* D6

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[263]This reflects the 'commonsense' morality espoused by Wear AN, Brahms D. At the coalface: to treat or not to treat: the legal, ethical and therapeutic considerations of treatment refusal. *J.Med.Ethics* 1991;**17:**131-135.
[264]The patient was described as not just having cerebral palsy but being completely blind, completely deaf and very small and underweight.
[265]EEG stands for electro-encephalogram, a test which depicts the electrical activity of various parts of the brain. A complete absence of activity indicates that the brain is dead.

Doctors who allowed relatives to overrule their clinical judgment failed to see this could cause problems for the future although several regretted the erosion of trust in doctors:

> *I thought it was inappropriate to carry on treating the patient and the son was firmly opposed to that decision. It wasn't conflict because I went along with it because if they have got firmly expressed views, I think it is better to give it a go.* A6

> *I'm not sure whether people totally trust their Doctor as they used to.* D13

There was recognition that relatives may have their own agenda:

> *We actually had...three or four cases of suspicious burns. In that situation you don't care what the relative says, you treat the patients...one of these young brides who was admitted with very extensive burns...the sooner you get rid of that burn tissue the better. But what happens is you end up with maybe an 80% burn and (then) they have an 80% open wound.* B9[266]

> *I'm wary of relatives who say, oh she really wouldn't want it...(and she has a big house all to herself and we will inherit it).* D8

> *Conflicts are normally nothing to do with medical issues but to do with family dynamics.* A36

2.5.1.2.2 Patient preference

The principle of autonomy was given great weight by many of the doctors and patient refusal would be recognised:

> *Patients are perfectly at liberty to (refuse). I tend to accept that...providing they understand. Then it's an informed decision and we can't assume just because we are doctors and that we have treatments available to us that might benefit a particular patient and therefore that patient should have it.* B5

> *She was in a bad way, bleeding a lot, and she said she was a Jehovah's Witness ...to have her on the operating table, exsanguinating and not being able to transfuse was difficult...I've never had one die on me - but if that particular girl did, that would have been unfortunate for her and her family but I would have had no personal emotional feelings.* A1

One consultant described a situation similar to ones where the courts have been petitioned for authority to proceed by the doctors in charge of the patient's care:

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[266]A consultant, who had practised in an area with a high Asian population, speaking of injuries which could have been murder or attempted murder.

Some years ago... a woman who was in labour...it wasn't going very well...we suggested Caesarian delivery, and she refused and labour continued and eventually she gave birth to a healthy baby...She withheld consent and that was that. A1

Conflicts between family members could also be apparent:

A lady, who's dying - at risk of sudden death from an aortic aneurism.[267] *She's asked for a long time for dialysis to stop but her husband is very much against this...so she's stopped asking.* A30

A young lad who decided that he didn't want any more dialysis and his wife vehemently disagreed with him and was extremely traumatised by it. He was traumatised by her upset but nevertheless wasn't changed in his decision by the way she felt about it. The nursing staff of the dialysis unit were extremely upset about it, the Doctors were extremely upset about it...I was upset by it as well. A15

It is interesting to note the apparently opposite approaches the patients concerned take towards the family. One places her own wishes subordinate to those of her family, the other places his own preferences before anyone else's.[268]

Three consultants raised the issue of children refusing treatment.[269] All wished to respect the child's views:

You have to take it individually because the child's intellectual capacity will vary naturally. I have really quite disabled children where...one would involve the consultant paediatrician and...psychologists...If...the child was expressing their own informed opinion then I would...respect the child's wishes. B16

A 17 year old boy who doesn't want (dialysis)...in the care of the local authority...I have very many legal documents saying I am required to treat this patient...I have tried to point out...that is all very well but I don't know how I could practically do it without sedating (him) 24 hours a day. A34

We do not take the parents' views as proxy for the child - they're the parents' views...as soon as the child is old enough (their views) may have to be taken into account. C14

These examples raise the question as to the extent to which a child's views should be determinative when the refusal of treatment will lead to death. Can children have sufficient decision-making capacity to choose death?

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[267]An aortic aneurism is where the aorta, one of the main arteries of the heart, has a weakness making it liable to rupture upon which the patient haemorrhages to death in a matter of a few minutes.

[268]Whether the age of the patient's had significance as regarding personal conduct is a question beyond the scope of this thesis but would be interesting to investigate given the markedly consumerist, and allegedly selfish society we now live in.

[269]See *Re R (A Minor)(Wardship: Consent to Medical Treatment*) [1992] Fam 11 and *Re W (a minor)(medical treatment)* [1993] Fam 64 regarding refusal of treatment by children and *Re E (A Minor)(Wardship: Medical Treatment)* [1993] 1 FLR 386 regarding child and parental refusal of blood transfusion which confirm that children's refusal of medical treatment will not be supported by the courts if the court believes treatment is in their best interests.

If the child does have the requisite level of understanding and competence as judged by the treating doctor, should the decision be subjected to independent review even if it falls within the 'band of reasonableness'?

2.5.1.2.3 Patient expectations

Several consultants mentioned potential conflict with patients over demands for inappropriate tests or treatment. Patients were felt to be better informed about healthcare than before but this led to unrealistic expectations:

> *They think they ought to have a brain scan because of headaches and my analysis ...was that the patient was clinically depressed...these were not headaches with the pains...typical of organic disease.* C1

Sometimes unrealistic demands resulted from a lack of medical knowledge to interpret the huge amount of healthcare/medical information now available appropriately. Some demands might be medically valid but financially unrealistic because of resource constraints:

> *Relatives of patients say, 'I've been searching the Internet and I've come up with these new treatments - why aren't my relatives on this?'* B2

When faced with such questions it seemed clear that the answer given by the consultant might vary according to whether he or she was prepared to be open about financial constraints. To reduce conflict the impression may be given that the alternatives were less appropriate for the patient. Sometimes, questioning patients would be sent for a second medical opinion:

> *I recently had a 91 year old with a hip problem that could be treated with a hip replacement. She also has severe airway disease and severe cardiac condition...she insisted on being treated so I've sent her for a second opinion.* D10

The second medical opinion approach was used often as a way to secure confirmation of the original treatment plan. However, as Doctor D10 explained, if the second opinion was in favour of treating, he would then review the patient again, hoping that the time delay would eventually encourage her to change her mind. If she didn't then he would be prepared to put her onto the waiting list for surgery.

2.5.1.2.4 Patient 'merit'

Another consultant described the case of a young man who had 'fallen' from a train, been badly electrocuted, suffered multiple injuries but his head had escaped injury. During resuscitation in Casualty, one of the psychiatrists came in and recognised the patient as a *'significantly bad schizophrenic with suicidal tendencies'* who had obviously jumped, not fallen, from the train...

It was then a question of how aggressive we were going to be. What happened was, he recovered and remained a bad schizophrenic with suicidal tendencies. B13

2.5.1.3 Professional Disagreements

Conflict with colleagues as to what was the right course of action was often a possibility since a patient will often be under the care of more than one consultant but good communication could avoid problems:

I usually feel if I've been honest...any difficulties have been resolved...it wasn't certain offering dialysis was going to be the right thing...my colleague was very uncomfortable about instituting dialysis, he was looking after her at the time...subsequently, her own kidneys picked up again and it wasn't necessary. A2

We discuss things...but in the hospitals up the road, they're all at each other...because they are having to fight for resources and fight for survival. D2

It's usually possible for everyone to agree with a bit of sensible debate. D7

A few identified religious extremism as a source of conflict with colleagues - an issue identified in *Bland* as preventing doctors exercising 'their own discretion in accordance with medical ethics'[270]:

Occasionally, a member of staff may have a particular religious or philosophical view about what is and is not okay that is fixed and non-changeable. B11

I have encountered extremists of both sorts: who would not treat and who would. C9

Several consultants identified conflict with nursing staff as more common than with fellow doctors possibly because the consultants took a more objective approach than the nurses who focused on caring for the patient and family as a whole:

Nursing staff...are usually keener to withdraw treatment sooner because they spend so much time with the relatives and they see themselves as the patient's advocate. A6

One consultant described his decision to try to save the life of a three year old boy with 90 % burns to his body:

It was a question of whether the staff were ready for it...they weren't...the family couldn't get the support...from the nursing staff. We had a lot of people saying you're playing God by treating this child whereas we were saying we're not playing God by treating the child, we'd be playing God by not treating the child because death would be certain. B9

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[270] *Airedale NHS Trust v Bland* [1993] AC 789 per Lord Browne-Wilkinson at p880.

2.5.1.4 Fear of litigation

Sometimes, to avoid conflict, treatment would be continued or implemented but unenthusiastically:

> *I've certainly not been over vigorous in my resuscitation...I don't think the nurses who cared for the child wanted to do it; they sidled up to me and said 'they're not breathing'...not that they were in any hurry to do it. (It was) a slow code situation.* A13

One consultant described an incident where normal professional behaviour was inhibited by the fear of 'the policeman over your shoulder':

> *I had a very disturbing case where...nobody would discuss what was going to happen to this patient...I would normally take a team decision...whether to pursue resuscitation...He was probably brain-dead...Nobody was prepared to talk...We ended up operating - he died on the table. I discovered afterwards that Casualty was being videoed, there are monitors and videos in the bays so logical decisions couldn't be made.* A27

It was clear that most doctors felt that patients were encouraged to complain following the introduction of the Patients' Charter:

> *I occasionally get into the complaints procedure with a patient if they don't feel they're getting what they need...it's because they are demanding something that's not appropriate.* A4

> *We've got a problem with one couple who want IVF. The man's in Rampton - gbh, drugs, heroin addict and alcoholic in the past. He'd been beaten round the testicles. She had two kids in care. Under the HFEA we have to consider the welfare of any child that will be born.*[271] A29

A few of the doctors mentioned concern over the legal implications of their actions:

> *We've recently been told...we can section people for anorexia for force feeding. We've almost been instructed to do it. It was a very clear statement that it is permissible to give a treatment under the Mental Health Act and you would be in great difficulty in the courts if you allowed someone to die.* A4

> *One or two (patients) who have asked for a sort of euthanasia which I haven't been able to offer.* A24[272]

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[271] 'gbh' stands for Grievous Bodily Harm (s18 Offences Against the Person Act 1861). Rampton is one of the three Special Hospitals in the UK where violent criminal offenders who have been sectioned under the Mental Health Act 1983 are sent. IVF is in-vitro fertilisation. HFEA is the Human Fertilisation and Embryology Act 1990.

[272] The issue of whether, if euthanasia were legalised, they would carry it out was deliberately not explored.

Sometimes, doctors inadvertently made potentially unlawful decisions:

> *A case of 'nearly brainstem death' that wasn't quite because he had the ability to take a few breaths every minute so didn't quite fulfil the criteria. I said it was futile...but the mother felt strongly life was life at any cost...but she came round but by then he was brainstem dead so it wasn't an issue...but I'm not obliged to give futile treatment.* A31

One consultant described a patient where doubt over the woman's competence should probably have been assessed independently prior to sterilisation by hysterectomy. It was likely that the woman was held competent by the treating doctors because they felt that the operation was in her best interests anyhow:

> *I've been involved as an expert in a case over a woman...there was some doubt that she wasn't going to be competent, but she was. She opted for sterilisation but it was very much that pressure was put on her to have the operation and she changed her mind and is now suing.* B19

One case, in particular, stood out. The decision was presented as based on her best interests although, as a competent patient, she should have been involved in the decision not to have antibiotics to treat the septicaemia which killed her.[273] In reality, it seemed based on the best interests of the consultant:

> *A young 20 year old girl...congenital deformity...skin...heavily colonised with bacteria and fungi to such an extent that she smelt terrible, you couldn't go in that room without gagging...She had, as a result...become blind, and deaf. She communicated by sign language by feeling your fingers. You couldn't communicate with this girl without touching her. So you had the natural abhorrence that came from the smell and then the touch factor. She was mentally competent. She...travelled underneath a blanket because of her appearance...Infection spread from the skin to the blood stream, and a decision had to be made as to whether we should actually treat her...(Her mother) had quite strong views...wanted us to treat her. Ultimately mother agreed we shouldn't treat her but it took her a lot of time to make that decision.* A35

2.5.2 Discussion

Patient autonomy was considered to be highly important but sometimes seemed infringed by doctors or relatives. Expecting doctors to make decisions about withholding and withdrawing treatment places them under a heavy burden - possibly evidence of failure to respect doctors' own needs. A variety of coping mechanisms were adopted but for some, it was easier to practice bad medicine by failing to withhold/withdraw treatment appropriately than have conflict. There was clear commitment to patient 'best interests' but sometimes this was interpreted as what was best for the whole family or best for the healthcare team.

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[273]The septicaemia was described as easily treatable with standard antibiotics.

There was concern over the legal ramifications of decision-making and possibly undue reliance on the belief that provided their peers did not condemn them, it was acceptable. Using 'slow codes' or 'unenthusiastic' treatment as a way to appear to have 'done everything possible' was not uncommon but fails to respect patients by breaching the principle of fidelity[274] and exposing them to inappropriate interventions. It contravenes the benefit-burden balance since, presumably, treatment is considered futile or unduly burdensome hence the benefit can only be in protecting the doctor from litigation or in reassuring relatives.

Regarding the last patient described, it is extremely concerning that the non-treatment decision was not reviewed by the courts assuming that the doctors could rely upon therapeutic privilege to avoid involving the patient herself.[275] It would involve a novel point of law: whether the courts or anyone else has jurisdiction to make healthcare decisions on behalf of a competent patient where the barriers to eliciting the patient's views are psychologically insurmountable to the carers. Whether withholding antibiotics would have been found in her best interests is debatable. The court might have recognised that it was in the interests of the staff involved with her care but whether it would have approved withholding treatment for such a reason is doubtful. Such a step might be for parliament alone.[276] As it was, the decision-making process seems legally and ethically unsupportable. It is important to note that there was no suggestion that the patient was incompetent. Her condition had caused blindness and deafness, but she was able to communicate with her mother. Waiting until her condition had deteriorated so that she was unable to participate in her treatment decisions seems extraordinary behaviour on the part of the doctors particularly since they recognised that her mother, to whom they then turned for 'approval' of their actions (or omissions) was very reluctant to agree that she should be 'treated to die'. It would appear that the doctors realised that their care plan was challengeable and wished to avoid this by gaining the mother's agreement. In other words, they were practising defensively.

2.6 Conclusion

Sound treatment decisions can only be made when it is recognised that healthcare ethics is not solely about doctor-patient relationships. Social policy and political ideology, influenced by lobbyists, affect resource allocation.[277] More openness is needed by those involved in the resource allocation process. The NHS is manipulated for political gains, but disguising the problems of limited resources and reduced (Conservative) government commitment to the welfare state as measures to increase public choice failed the public. It did grave disservice to clinicians who try to achieve the best for individual patients. The competition culture produced competitiveness and selfishness in individuals regarding public resources.[278] The passing of power to unelected managers was 'not only harmful to patients, but also massively wasteful'.[279] The limits to what

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[274]See: Beauchamp TL, Childress JF. *Principles of Biomedical Ethics* Fourth Edition 1994 Oxford University Press, Oxford, in particular, at pp 429-440.

[275]As was suggested in *Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810.

[276]The Law Commission possibly suggests that the interests of those treating the patient could be relevant when they spoke of their recommendation being 'directed to those cases where the 'best interests' criterion cannot be invoked to resolve the dilemma of treatment providers'. Law Commission for England and Wales. Report No 231: Mental Incapaciy 1995 HMSO, London at para 6.20.

[277]Campbell AV. *Nonesuch* (University of Bristol Magazine) Autumn 1996 pp 27-29.

[278]Sorell T. Morality, consumerism and the internal market in healthcare. *J.Med. Ethics* 1997;**23:**71-6.

[279]Black D. Paying for health. *J.Med.Ethics* 1991;**17:**117-123 at p123.

any country, or person, can spend on healthcare have to be recognised but the extent to which financial considerations should be decisive is questionable. Geographical differences in the healthcare provided should be as unacceptable as differences based on gender, race, social importance or ability/disability. Doctors should not feel viewed with suspicion. Their contribution to the debate is vitally important as possessors, and imparters, of medical information. Cost-effectiveness is only part of the debate which needs to address the potential efficacy of treatment.

Any proposals to improve the decision-making process regarding withholding or withdrawing medical treatment will have to address the conflicts and differences demonstrated in this chapter. The proposals must provide a way for such decisions to have greater acceptability to the patients themselves, their families (or significant others); the healthcare team and to society in general than the present process produces. This will reduce conflict which is emotionally, and sometimes financially, expensive for the parties concerned and for society. Strengthening autonomy will be important but also a way to achieve fairness and proportionality must be sought. Openness, not just about treatment options, but about resource limitations and the choices which have to be made also seems important in the interests of maintaining a democratic and just society. It will be necessary to decide the extent to which children and adults of questionable competence can determine their own treatment options. Some of the examples shown suggest that patient autonomy only receives strong support when the patient agrees with what the doctor considers appropriate. Autonomy is abused by doctors who wish to exclude the decision-making process from independent scrutiny. Openness about the barriers to good decision-making is necessary. There is potential for the decision-making process to be affected by the information available as with the 'train jumper' described above. It will be necessary in an age of information-overload to identify which information is relevant and should be considered and which prejudices or distorts the decision-making process. The next two chapters examine in depth the current decision-making process.

CHAPTER THREE

WITHHOLDING MEDICAL TREATMENT

This chapter describes how and when medical treatment is withheld. The outcome of withholding treatment can vary and analysis will be made accordingly. It will examine how decisions to withhold treatment are made in general, grouping them according to whether the outcome of the non-treatment decision is imminent and certain death; eventual death or reduced quality of life. Then the way the consultants interviewed for this thesis said they made decisions to withhold treatment in individual cases is considered.

3.1 Outcome of Imminent and Certain Death

This group includes clinical situations such as very premature babies, cardiac arrest, major haemorrhage[1] and major trauma.[2]

3.1.1 Babies

McHaffie and Fowlie suggest that there are three groups of babies for whom withholding medical treatment may be considered: the congenitally malformed where death is inevitable regardless of treatment; the severely impaired 'whose prognosis for a future quality of life is so poor that non-treatment is considered preferable to continued existence' and the severely impaired who do not require intensive treatment to support life but whose 'quality of life is expected to be extremely poor'.[3] Others recognise up to eight subgroups where non-treatment may be 'morally preferable'.[4] The nature of the debate is, essentially, 'Sanctity of Life versus Quality of Life.'[5] Such debates are unresolvable since those who value all life equally, regardless of quality, will not be reconciled to the view that living might not be in the infant's 'best interests'.[6] Others accept that improved success in reducing neonatal mortality means it is 'inevitable and proper that an increasing *proportion* of the deaths will follow 'non-treatment decisions''.[7]

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[1]For instance, as a result of trauma, aortic aneurysm (rupturing of the aortic blood vessel to the heart normally caused by heart disease) or, rarely, haemorrhagic viral infections (infections caused by viruses which destroy the red blood cells causing major bleeding into the internal organs and tissues of the body).

[2]For instance, severe head injury, amputation or extensive burns.

[3]McHaffie HE & Fowlie PW. *Life, Death and Decisions: a reflection on neonatal practice.* 1996 Hochland and Hochland, Cheshire at pp7-8.

[4]Sauer PJJ. Ethical decisions in neonatal intensive care units: the Dutch experience. *Pediatrics*, 1992;**90**,5:729-732. Reporting on the approach taken by the Dutch Paediatric Association. McHaffie op cit n3 at p8, lists the categories.

[5]Separovic ZP. Massa carnis or human beings? in *Jus Medicum* 1984, Centrum Voor Medish Recht, Rijkunwersiteit, Gent pp169-172 at p171.

[6]Long T. Infanticide for handicapped infants: sometimes it's a metaphysical dispute. *J.Med.Ethics* 1988; **14**:79-81 at pp70-80. This article discusses the stances taken by Ramsey (sanctity of life) and Kuhse & Singer (Quality of Life). See: Ramsey P. *Ethics at the edges of life*. 1978 New Haven, Yale University Press and Kuhse H, Singer P. For sometimes letting - and helping - die. *Law Medicine and Health care* 1986; **3**,4:149-153.

[7]Campbell AGM. Treatment dilemmas in neonatal care. *Annals of the New York Academy of Science.* 1988;**530**:92-103 at p96 (his emphasis). He reports that withholding/withdrawing treatment was directly related to the death of the neonate in 51% of cases. He also recognises (at p96) the difficulty, little recognised by society, of the 'particularly difficult and poignant dilemma...posed by the neonatal survivors of failed late abortions'. His findings are supported by Balfour-Lyn and Tasker study which found that almost two-thirds of deaths in a paediatric intensive care unit were linked to a decision to limit medical treatment: Balfour-Lyn IM & Tasker RC. Futility and death in medical intensive care. *J.Med.Ethics* 1996; **22**:279-281.

Often the cut-off point for attempting to save life[8] is gestation of 24 weeks or less[9] or birthweight of 500 grams or under[10] because evidence indicates that such neonates either die despite full technological intervention, or survive with major, very life-impairing handicaps. Within the range 500-1000 grams, survival rates remain very low and the presence of sensorineural disability[11] very high.[12] Technological and pharmaceutical improvements have improved outcomes,[13] resulting in 'increasing willingness and ability to treat tiny babies'.[14] Blank has concluded that decisions are made in the delivery room by the doctor and that parental involvement is a myth.[15] If correct, once the baby has separate existence, the mother is excluded from the decision-making process by a profession which has created for itself a prerogative over life and death. The conferring of legal personhood on the infant does not fully explain how, in this country, the power of life and death over a handicapped foetus is vested in women right up to the time of delivery yet women can be marginalised after delivery because doctors are exercising a power which they have conferred on themselves and which the courts have been unable or unwilling to interfere with.[16]

Bohin believes that the U.K. adopts a 'conservative policy towards infants born before 24 weeks gestation and...resources expended on them are limited'.[17] Some infants may be the survivors of failed late abortions and this can affect the care they receive.[18] Few survivors are monitored: '(o)ur ability to assess and report the outcome of very low birthweight infants has lagged behind our willingness to resuscitate them'.[19] Doyal concludes that treatment should continue since the low numbers of those with severe handicaps does not over-burden society.[20] His brief examination of the ethics of societal resource allocation seems typical of many medically-directed articles. Placing the medical model paramount indicates a belief that society should not interfere with what doctors consider appropriate. Three approaches to instigating treatment are possible: the *wait until certainty strategy* (ie. treat all infants vigorously until it is virtually certain they are not benefiting or are being harmed); the *statistical probability strategy* (ie. withhold treatment from all infants where the prognosis is 'uncertain or grim') and lastly, the *individualized prognostic strategy* (ie. start treating in all cases but review regularly for indications of certain death or severe brain damage).[21]

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[8]I.e. the adoption of the curative model of care.

[9]Which coincides with the provisions of the Abortion Act 1967 (s1(1)(a)) for legal terminations of pregnancy in the absence of handicap or grave risk to the woman.

[10]Normal birth weight is in the region of 2499 grams or more.

[11]For instance, as evidenced by cerebral palsy, deafness, blindness or delayed development.

[12]Doyal L et al. Improved outcome into the 1990s for infants weighing 500-999 grams at birth. *Archives of Disease in Childhood* 1997;77:F91-F94.

[13]Over the last twenty years, such developments have led to greatly improved prognosis for neonates in this weight range both in terms of survival and the absence of major disability although the lower weight range neonates (500-750g) still have higher sensorineural disability rates than those with birthweights over 750g. Doyal L et al op cit n12, at F94. Also, Hack M et al. School age outcomes in children with birth weights under 750 g. *N.Eng.J.Med* 1994;**331:**753-9.

[14]Doyal et al op cit n12, at pF93. However, the apparent increase in willingness to treat such low birthweight infants is not uniform and when treatment is refused on the grounds of weight the parents may be understandably upset as for instance when treatment was refused for a neonate weighing only 567 grams: Anon. Scottish inquiry vindicates decision not to resuscitate baby. *BMJ* 1997;**315**:9. See also: Cramb A. Doctor left my premature baby to die. *The Daily Telegraph* Tuesday, June 10, 1997.

[15]Blank RH. International Symposium on Critically Ill Newborns. *J.Legal.Med.* 1995; **16:**183-188 at p185.

[16]The legal situation will be examined in a later chapter. For a critique of the anomalies of this situation see *McHaffie HE., Fowlie PW.* Life, Death and Decisions: a reflection on neonatal practice. 1996 Hochland and Hochland, Cheshire at pp5-6.

[17]Bohin S et al. Impact of extremely immature infants on neonatal services. *Arch.Dis.Child.*1996:**74**:F110-F113 at F113.

[18]Campbell AGM. Treatment dilemmas in neonatal care. *Annals of the New York Academy of Science.* 1988;**530:**92-103 at p96. The author of this thesis was told by a young nurse of such an incident in which she was involved. She was reprimanded by her manager for taking the infant to the neonatal unit where it died a few hours later.

[19]Rennie J.M. Perinatal Management at the lower margin of viability. *Arch.Dis.Child* 1996;**74**:F214-F218 at F215.

[20]Doyal et al op cit n12, at pF94. He suggests that in 1991-2, about 8 children who had had extremely low birth weight would survive with severe handicap compared with about 1000 children born with normal birth weight (NBW) yet with severe handicap. He does not attempt to discuss the reasons for the severe handicap in the NBW children. However, other authors indicate that there has been an increase in the number of children with cerebral palsy and disability as a result of the increased use of neonatal intensive care: Oakley A. Essays on Women, Medicine and Health. 1993 Edinburgh University Press, Edinburgh at p118.

[21]Rhoden NK. In: Treating Baby Doe: the ethics of uncertainty. *Hastings Centre Report,* 1986;**16:**34-42.

Better outcomes are obtained by specialist centres[22] with parents receiving the most current information possible enabling informed decisions to be made[23] some opting for non-treatment with others wanting everything possible.[24] Rennie suggests decisions are strongly parent-led, a model apparently deferring clinical experience to parental preference although clinical and parental views may clash.[25] Once a viable infant is born, should parents be able to bar treatment?[26] Parental decision-making never before faced such dilemmas. Parental freedom of choice is likely to be reduced by the growth in evidence-based medicine. Since NHS resources are limited, and often outcomes are 'appalling'[27], deciding on the basis of outcome predictors may seem appropriate.[28] However, Oakley is concerned that most policies regarding non-treatment of neonates ignore differences between populations regarding birthweight and congenital abnormality.[29] Inadvertent discrimination could occur. Whilst perinatal mortality seems linked to the mother's social class, no study seems to have examined whether there is a link between parental social class and the decision to withhold active treatment although there is some evidence that lower classes are more tolerant of handicap than higher, more professional classes.[30] Oakley suggests that statistics are misused to make a 'case based on a set of values and assumptions about *who* are the appropriate people to promote health in any community, and about the allocation of moral responsibility for health to particular groups within it'.[31]

Resource allocation by health authorities relies upon clinicians deciding whom to treat.[32] Rationing, to the detriment of individual neonates and emotional costs to the healthcare team, occurs due to shortage of cots.[33] Avery reports that '(p)ublic policy has placed a steady cost squeeze on care of the tiny premature, regardless of ethical intent' and that Canadian researchers had suggested care was only cost-effective for babies weighing more than 1250g.[34] Such data quickly becomes obsolete because of rapid advances in what is technologically achievable[35] making the withholding treatment debate difficult.[36]

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[22]Following the reforms introduced by the National Health Service and Community Care Act 1990 this was frequently impossible due to the extra- contractual nature of such referrals and the shortage of intensive care cots.

[23]Rennie JM op cit n19. Her research shows that neonates born between 23 weeks and 26 weeks, 6 days gestation have marginal viability: 50% die and 50% survive with some disability. Her findings are supported by others: Hodges D et al have analysed the effect of place of treatment on survival of premature babies and concluded that infants who received all their perinatal care at one of the five large centres had significantly better outcomes than infants treated throughout at one of the 12 smaller units in the Trent region: Hodges D et al. Survival and place of treatment after premature delivery *Arch.Dis.Child.*1991;**66**:408-411.

[24]Rennie, op cit n19 at F215, considers that it is 'reasonable not to...resuscitate babies of 23 and 24 weeks gestational age..if the parents agree, and the baby is born in poor condition' and would advise against resuscitation at 22 weeks and in favour at 25 weeks. In contrast, Roberton considers that 'the case is proved that we must look after, properly, babies of a birth weight greater than 500g or a gestation of 24 weeks or more. Furthermore, for babies of 22 or 23 weeks gestation who are in a satisfactory condition at delivery, or those whose birthweight is just below 500g and who are also in a satisfactory condition, a long term neurologically intact survivor is also a distinct possibility, and such babies should also receive appropriate levels of care'. Roberton NCR. Should we look after babies less than 800g? *Arch.Dis.Child.*1993:**68**:326-329 at p328.

[25]For instance, where the parents of the baby refuse resuscitation at 26 weeks when there is a reasonable chance of survival without handicap or where the clinician has agreed pre-delivery not to attempt resuscitation of a 24 week gestation infant who is subsequently born with a better clinical picture than anticipated. Rennie, op cit n19 at F215. With the pre-term, low weight baby, there is no time to get the authority of the court when the parents insist on treatment being withheld but doctors would be able to rely upon the doctrine of necessity.

[26]For instance regarding babies with Down's syndrome requiring heart or abdominal surgery if they are to live: *Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421. Delays in instituting resuscitation and intensive care therapy are fatal. Relevant case law is discussed in a later chapter.

[27]Rennie op cit n19, at F216.

[28]Rennie, ibid, at F217 suggests that more information on clinical outcomes following resuscitation of low birthweight neonates is needed and may be forthcoming in the *Confidential Enquiry into Stillbirths and Deaths in Infancy* or from the current UK study of very premature infants (EPICure).

[29]Oakley A. *Essays on Women, Medicine and Health.* 1993 Edinburgh University Press, Edinburgh. See pp112-3.

[30]Li L, Moore D. Acceptance of Disability and its correlates. *J.Soc.Psychology* 1998;**138,**1:13-25. See also: Sheppardson B. Abortion and Euthanasia of Down's Syndrome Children - the Parents' View. *J.Med.Ethics* 1983;**9:**152-7.

[31]Oakley, op cit n29 at p122 (her emphasis).

[32]Care for maternity services including neonatal care, is, on the whole, funded as a block based upon evidence of the previous year's figures.

[33]Bruggen P. *Who Cares? True Stories of the NHS Reforms.* 1997 Jon Carpenter Publishing, Charlbury at pp199-202.

[34]Avery GB. Ethical Dilemmas in the Treatment of the Extremely Low Birth Weight Infant. *Clinics in Perinatology* 1987;**14**,2:360-5 at p362.

[35]Ibid, at p361.

[36]Ibid, at p363.

Clinical evidence seems the main criterion for deciding to treat/not treat these neonates coming before any consideration of 'best interests',[37] i.e. before application of the principles of beneficence or non-maleficence.[38] However, it can be trumped by parental preference which is not necessarily the same as the child's 'best interests'. Nelson considers that treatment can be withheld if doctors believe it is 'contrary to a child's best interests, is futile, harmful or disproportionately burdensome, but only after completing a process aimed at reaching an honest agreement and specifying the parents' and physician's values'.[39] Nelson cautions that the decision may incorporate the doctor's 'value judgment' and '(t)he parents' values may not be heard or properly respected if this value judgment is hidden beneath the cloak of medical futility'.[40] Knowing that a severely-disabled life is very unpleasant does not necessarily mean that death is preferable. As Devettere says, '(w)hat we would consider a terrible loss may not be experienced as such a loss by him because he has never had what he now lacks'.[41] Withholding treatment means deciding that the harm (maleficence) of treating outweighs the benefits yet this conclusion is only possible if life is considered of limited value.[42] If any life is considered an overriding 'good' anything preserving it must be intrinsically good despite appearing to be intrusive and burdensome. Curative treatment is inappropriate where evidence indicates palliation. In the case of 'Baby K'[43], had the clinical appropriateness of ventilating her been considered first, it would not have been implemented.[44] She clearly received inappropriate treatment but access to SCBUs[45] still appears to be 'first come, first served' disregarding viability.[46] However, recognition of legitimate resource constraints does not imply acceptance of infanticide. In Holland, two physicians were prosecuted for deliberately causing the death of neonates by lethal injection but were acquitted as their action was held 'medically necessary'.[47] This is a step too far for many.

3.1.2 The critically-ill and withholding resuscitation

Decisions to withhold resuscitation[48] are made in a variety of situations: major heart disease; untreatable cancer or simply 'old age'.[49] The most influential factor is the predicted outcome of attempting resuscitation.[50]

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[37]Doyal L, Wilsher D. Towards guidelines for withholding and withdrawing of life prolonging treatment in neonatal medicine. *Arch.Dis.Childhood*, 1994:**70**,1:F66-70 at F66. Doyal and Wilsher suggest withholding treatment is only legally and ethically acceptable if the decision has been made 'in the child's best interests'.

[38]In 1997, the Royal College of Child Health and Paediatrics, in an attempt to provide some guidance and uniformity of decision-making, issued a set of guidelines which listed five categories of patient where it would be appropriate to withhold or withdraw treatment. These are (1) the Brain Dead Child, (2) the Permanent Vegetative State, (3) the 'No Chance' situation, (4) the 'No Purpose' situation and (5) the 'Unbearable' situation. These guidelines will be considered later.

[39]Nelson LJ. Ethics and the provision of futile, harmful, or burdensome treatment to children. *Crit.Care Med.* 1992;**20**,3:427-433 at p427.

[40]Ibid, at p428.

[41]Devettere RJ. *Practical Decision Making in Health Care Ethics.* 1995 Georgetown University Press, Washington DC, USA at p329.

[42]McHaffie op cit n16, at p10 is concerned that if, in certain circumstances 'we ourselves would opt for death rather than a seriously impaired life, we are in effect saying that some lives are not worth prolonging'.

[43]The 'Baby K' story is told by several authors. An excellent discussion is to be found in Devettere op cit n41 at pp352-6.

[44]Luce JM Physicians do not have a responsibility to provide futile or unreasonable care if a patient or family insists. *Crit.Care Med.*1995;**2**:760-766.

[45]Special Care Baby Units. The term is employed to include Neonatal Intensive Care Units.

[46]It is rare to have a hospital having two or more premature babies delivered at the same time when only one cot is available. Such instances normally occur in multiple births and these have usually been detected prior to delivery so that availability of ITU cots is assessed although situations can arise where one twin is treated at the delivery site and the other has to be referred elsewhere.

[47]van der Heide A et al. Medical end-of-life decisions made for neonates and infants in the Netherlands. 1997 *The Lancet* **350**:251-5, at p255. The survey reported found that 8% of deaths in neonates and infants was the result of lethal injection.

[48]The decision not to attempt resuscitation in the event of a cardiac arrest is generally framed as a 'Do Not Attempt Resuscitation' Order (DNAR).

[49]Crimmins TJ. Ethical Issues in Adult Resuscitation. *Annals Emerg.Med.*1993;**22**,2:229-235 at p231.

[50]Audits have shown that resuscitation attempts in the UK, USA and Europe will restore life in 44% of cases but only 15% will recover sufficiently to be discharged from hospital and fewer still will be alive a year later. Saklayan M et al. In-hospital Cardiopulmonary Resuscitation. *Medicine* 1995;74:163-175 at pp168-172.

Physicians often find directly discussing this issue with patients difficult[51] because it confronts both with the inevitability of death[52] but discomfort should not prevent discussion occurring.[53] Unrealistic expectations about resuscitation outcomes may influence patient wishes.[54] Proxy decisions (including the treating physician) and patient's wishes often differ.[55] If the patient is to make an informed decision s/he needs honest and accurate information.[56] How information is presented can bias the decision.[57] A decision not to be resuscitated may fail to reflect the patient's true desires and could cause distress the patient feels unable or ashamed to express.[58] Alternatively, some physicians may initiate resuscitation against the patient's wishes,[59] even when clinically futile[60] thereby failing to withhold treatment appropriately.[61] There is a suggestion that the doctor must 'do something - don't do nothing'[62] which, possibly because of the fear of litigation, bureaucracy, or personal failure means that doctors, particularly in the U.S.A., have been taught, 'don't let the patient die on your shift'.[63] Enabling the patient to 'die well' means recognising that 'life is not the ultimate good nor death the ultimate evil'.[64] However, the public seems to regard DNAR orders with suspicion.[65] In 1968, the media compared a medical director prepared to write DNAR orders to the commandants of Nazi concentration camps.[66] By the year 2000, little had changed and there was media outcry over a patient who was asked if she

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[51]Bedell SE & Delbanco TL. Choices about cardiopulmonary resuscitation in the hospital: when do physicians talk with patients? *NEJM* 1984;**310**:1089-93. Similarly, van Delden found that in only 14% of cases had the patient been involved in the making of their DNAR decision: van Delden JJM et al. Deciding not to resuscitate in Dutch hospital. *J.Med.Ethics* 1993;**19**:200-5. It has to be recognised that in Holland, if the decision is based on grounds of futility, the patient need not be involved (p203) but van Delden discovered that often, where 'futility' was cited, the physician did not really believe attempting resuscitation was futile so the conclusion can be made that 'futility' is used inappropriately, or a wider meaning of 'futile' was adopted.

[52]The consequence of withholding resuscitation is that, the 'death' of patient having already occurred, no attempt is made to reverse the clinical situation and restore life. An additional problem can be found in the cultural or religious background of the patient as to whether such a discussion is appropriate. The Jewish view, according to O'Donovan, is that 'the welfare of the patient takes precedence over all considerations' and nothing must be done to 'sap his confidence in recovery'. O'Donovan O. *Begotten or Made?* 1984 Oxford University Press, Oxford at p119.

[53]One study on decisions to forego life support in which it was stressed that patient autonomy was not to be violated found that NO discussions about the patient's wishes regarding resuscitation took place because either the patient never raised the issue; the patient raised the issue and the doctor resisted hearing it, or the doctor raised it but not emphatically enough to get an answer. Safar P et al. Philosophical, ethical and legal aspects of resuscitation medicine. *Critical Care Medicine* 1988;**16**:1068-1076 at 1072.

[54]Bruce-Jones PNE. Resuscitation decisions in the elderly: a discussion of current thinking. *J.Med.Ethics* 1996;**22:**286-291.

[55]Whitnack E. Letter: Substituted judgment and the decision to withhold life support. *Ann.Int.Med.*1991;**115**,9:743-5 at p744. She suggests that patients should be told that they would find themselves in Intensive Care following successful resuscitation with a tube in their mouth preventing speech plus a variety of other tubes, lines and catheters inserted; that they may have to be restrained; that they would 'move their bowels' in bed and that they may also have brain damage, heart damage and develop pneumonia, kidney failure, sepsis, haemorrhage. Seckler has concluded that proxy decisions frequently bear little resemblence to the decision the patient would have made him/herself: Secler AB. Substituted judgement: how accurate are proxy predictions. *Annals Intern.Med.* 1991;**115:**92-98.

[56]Liddle J et al. The views of elderly patients and their relatives on cardiopulmonary resuscitation. *J Royal Coll Physicians* 1994;**28**:228-9. This study of 100 patients after discharge found that 78% would have wanted CPR in the event of a cardiac arrest but only 11% were recorded as for resuscitation.

[57]Taylor EM et al. Patients' receipt and understanding of written information about a resuscitation policy. *Bioethics* 1998;**12**,1:64-76. Taylor evaluated the effectiveness of providing information in a booklet distributed to patients prior to hospital admission. Only 51% received the booklet; only 38% read it; only 27% understood it. Worryingly, 15% felt the DNAR policy may be misused in order to save money and a further 4% approved of resource allocation limiting the availability of resuscitation.

[58]For instance, the patient may wish resuscitation to take place even if the long-term prognosis is very poor as a 'successful' attempt may restore life long enough for his/her family to reach the hospital to say goodbye, or for the patient to see their first grandchild.

[59]The patient who has attempted suicide is not considered as having given a valid refusal to resuscitation and doctors and ambulance personnel would be considered to have failed in their legal and professional duties if they did nothing. Similarly, a patient request that resuscitative measures were not taken in the event of a cardiac arrest may not be valid if the patient lacked the capacity to give a valid refusal of treatment for reasons due to mental illness and any discussion about treatment can only hold weight if the patient has capacity to make decisions about their own healthcare.

[60]For instance, if the patient was known to have an aortic aneurism - once cardiac arrest occurs in such a patient cardiac output is impossible to restore.

[61]Asai A et al. Medical decisions concerning the end of life: a discussion with Japanese physicians. *J.Med.Ethics* 1997;**23**:323-7. He reported that whether or not DNAR orders were followed depended on whether the physician or relatives were present at the patient's bedside at the time the arrest occurred.

[62]Attempts to resuscitate may merely prolong the process of dying in 25% or more of cases. See: Thomas R et al. Cardiopulmonary resuscitation in a district general hospital. *Arch.Emerg.Med.* 1990;**7**:200-5 and Saklayan M. In hospital Cardiopulmonary Resuscitation. 1995 *Medicine* **74**:163-175. Reasons given are variously: the reluctance of doctors to accept death in young patients; the refusal of some doctors to acknowledge that their patients have reached the end of a terminal disease; failure to communicate the DNAR order; fear of medico-legal sanctions and the 'heroes'. Also, one survey found that of 300 patients, 86 were unsuitable for resuscitation yet only 26 had DNAR orders and only 10 of these orders were known to the nursing staff. Aarons E & Beeching N. Survey of Do-Not-Resuscitate orders in a district general hospital. *BMJ* 1991;**303**:1504.

[63]Safar P et al. Philosophical, ethical and legal aspects of resuscitation medicine. *Critical Care Medicine* 1988;**16**:1068-1076 at p1075.

[64]Handley A. Should we resuscitate? *Care of the Critically Ill* 1990;**6**:152-3 at p153.

[65]Do Not Attempt Resuscitation.

[66]Towers B. Public debate on issues of life and death. *J.Med.Ethics* 1983; **9:**113-5 at p113.

wished for resuscitation attempts to be made in the event of a cardiac arrest.[67] American patients are routinely asked such questions.[68] Theoretically, a DNAR order is fully compatible with continuing to give the highest level of other care.[69] In reality, care is often reduced and physio/speech therapy will be withdrawn because of pressure on these services.[70] Thus a valid decision based on clinical values results in an invalid decision grounded in economic values.

Also debatable is whether resuscitation research can be carried out on the 'dead' person without consent.[71] Those who favour doctors carrying out 'desperate, uncontrolled trials of novel pharmacologic and physical agents' suggest that if the treatment fails, the patient is no worse off and if it works the patient has benefited from having life restored.[72] The answer must be that if the patient refused resuscitation, any attempt to carry it out is non-consensual but if the patient did agree, once the usual protocol has failed, it may be permissible to try out novel treatment. The patient is rarely involved in the resuscitation decision so it seems that doctors could decide, regarding the same patient, to either withhold treatment as futile or to provide treatment mainly as a learning exercise.

Guidelines are important regarding the withholding of resuscitation.[73] All accept that DNAR orders should be reviewed regularly.[74] Factors to include are the quality of life prior to the illness (highly subjective and known only to the patient), the expected quality of life (medical and social) assuming recovery and the likelihood of resuscitation being successful. Hospitals are free to draw up individual protocols. Whilst the ethics of CPR in adults has been widely debated, less attention has been paid to children.[75] Unlike the elderly patient a resuscitated infant could potentially live sixty years or more.

3.1.3 The patient with major trauma/advanced disease and the withholding of life support

Hall suggests that ethical debate fails to understand the power of the adage, 'if the technology exists, use it'.[76] This emphasis continues because the 'paucity of knowledge about prognosis, compared to diagnosis causes physicians to seek a high standard of certainty before making decisions to withhold or withdraw therapy'.[77]

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[67]Hope J. Doctors 'pressured to stand back and let their patient die'. *Daily Mail* 28 June 2000.

[68]The Patient Self-Determination Act 1990 means American patients are asked these questions routinely.

[69]Many hospitals, following the advice of the UK Resuscitation Council and Ombudsman's criticism, have policies regarding how DNAR orders are to be made, how they are to be recorded. These often include a statement to the effect that the making of the order is compatible with the continuing of other care as appropriate to the patient's needs: Resuscitation Council (UK) *Decisions Relating to Cardiopulmonary Resuscitation: A joint statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing.* January 2001 Resuscitation Council (UK), London, para 15. All hospitals are now expected to have such policies: NHS Executive. *Resuscitation Policy* (HSC 2000./028) September 2000 Department of Health, London.

[70]Candy CE. Not for resuscitation: the Student nurses' viewpoint. *J.Advanced Nursing* 1991;**16:**136- 146 at p142.

[71]Safar P et al. Philosophical, ethical and legal aspects of resuscitation medicine. *Critical Care Medicine* 1988;**16**:1068-1076 at p1070. Suggestions were made that the 'emergency exception to consent' could be invoked but the American approach is that the concept of 'deferred consent' is adopted.

[72]Safar P et al. Philosophical, ethical and legal aspects of resuscitation medicine. *Critical Care Medicine* 1988;**16**:1068-1076 at p1070.

[73]In the UK the first BMA and RCN joint statement was issued which stated that it is appropriate to withhold resuscitation by means of a DNAR order where the patient's condition indicates that effective cardiopulmonary resuscitation (CPR) is unlikely to be effective; CPR is not in accord with the recorded sustained wishes of the patient who is mentally competent or successful CPR is likely to be followed by a length and quality of life which would not be acceptable to the patient. *Joint Statement on Cardiopulmonary Resuscitation* issued March 1993 (No 000 244) This was issued after the Chief Medical Officer wrote to hospitals following a complaint to the Health Service Ombudsman (PL/CMO(91)22) which will be discussed in a later chapter. More recent guidance has been issued since: Resuscitation Council (UK) op cit n69.

[74]Dr Peter Baskett, the acknowledged UK expert on resuscitation ethics suggests review should be conducted on an individual basis and could be 'weekly, daily or hourly'. Ethics in Cardiopulmonary Resuscitation. *Resuscitation* 1995;**25**:1-8.

[75]Davies JM & Reynolds BM. The ethics of cardiopulmonary resuscitation Background to decision making. *Arch.Dis.Child.*1992;**67**:1498-1501.

[76]Hall K. Intensive Care Ethics in Evolution. *Bioethics* 1997;**11**,3&4:241-5 at p241. Hall calls this the 'scientific ethic' and points out that intensive care medicine is 'a very recent branch of medicine, having its origins in the polio epidemic of the late 1950s'.

[77]Hall K. Intensive Care Ethics in Evolution. *Bioethics* 1997;**11**,(3&4):241-5 at p245.

Different cultures may adopt different stances.[78] The family of a terminally-ill Japanese patient may not sanction the withholding of treatment because this would constitute 'abandonment'.[79] Shortages of intensive care beds means some patients are denied access despite the appropriateness of care. Sometimes, inappropriate patients fill these beds as happens during influenza outbreaks.[80] Hall asserts that there is no ethical model which 'adequately addresses the role of technology, technical expertise and technical achievement' so the scientific ethic continues to be the model used. Hall argues that the distinction made in Asclepian medicine between the 'hopelessly ill' to whom no treatment should be given and the 'seriously ill where treatment was at the physician's discretion'[81] should replace the present 'ethos of aggressively subordinating Nature to human will'.[82] Patients with disabling conditions like motor neurone disease are frequently concerned that they will be subjected to ventilation and tube feeding against their will.[83] Devettere, likewise, is concerned at aggressive over-treatment, particularly of apparently competent elderly patients who have tried to refuse aggressive treatment.[84]

3.2 Outcome of Eventual Death

In some cases, death could be averted if treatment is given. Without treatment the patient will die within a matter of weeks.

3.2.1 The patient needing transplantation

Organ transplantations are increasingly successful but the number of available organs is limited.[85] Whilst dialysis is possible for the patient with renal failure, alternatives to transplantation are in their infancy with regards to heart and liver failure. There is currently no artificial alternative to lung transplantation. Kidney transplant patients report a better health related quality of life than dialysis patients.[86] Only certain patients are referred to transplantation units; few go onto the waiting list; many die waiting. The criteria identified by Collins to withhold the transplantation option include: co-morbid disease, malignancy, diabetes, infection, substance abuse, psychiatric illness and a lack of 'social support systems' with refusal usually dressed up as 'futility' even though 'rationing' is a more accurate descriptor.[87] He suggests 'rationing' is such an

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[78]For instance, in Japan, clinicians tend to treat even terminally ill patients aggressively (i.e. they adopt the curative model of care) even when the patient has indicated otherwise. Japanese physicians may disregard DNAR orders and may ventilate patients whose cancer is so advanced that they are comatose, because anything less is 'patient abandonment'. Asai A et al. Medical decisions concerning the end of life: a discussion with Japanese physicians. *J.Med.Ethics* 1997;**23**:323-7.

[79]Asai A, op cit n79 at p325. Asai explains that the decision falls to the family because Japanese doctors will not usually tell a patient if s/he has a terminal illness and they consider it more appropriate to discuss treatment options with the family even where the patient is competent.

[80]For instance, during the winter of 1999-2000.

[81]Hall K. Intensive Care Ethics in Evolution. *Bioethics* 1997;**11**,(3&4):241-5 at p243.

[82]Ibid, at p245.

[83]One such patient was Annie Lindsell who campaigned in favour of euthanasia. Her advance directive was recognised as determinative when her condition deteriorated to the point of considering ventilation.

[84]Devettere op cit n41. See, in particular, his account of the case of William Bartling at pp177-181.

[85]Collins EG et al. Decisions not to transplant: Futility or rationing. *J.Cardiovascular Nursing* 1995; **9**,3:23-9. Increased success rates and improved anti-rejection drugs mean that conditions where previously the patient would not have been considered for an organ transplant are now being treated. For instance, Collins et al report (at p23) that heart transplantation is now considered 'acceptable treatment therapy for patients with end-stage congestive heart failure' - a condition normally considered terminal. Survival rates quoted by Collins et al are 80% at one year and 40% at 12 years whereas survival without transplantation is under 50% at one year. Most organs come from dead donors so, with increased success in treating trauma injuries; low numbers carrying donor cards, and medical reluctance to request organ donation, usable organs are a scarce resource.

[86]Gudex CM. Health related quality of life in end-stage renal failure. *Quality of Life Research* 1995;**4**:359-366 at p365.

[87]Collins EG et al, n85 at p24. 'Co-morbid disease ' refers to existence of some other physiological disease in addition to the congestive heart failure.

unacceptable word in the U.S.A., policy makers cannot openly use it.[88] In Britain, the unavailability of organs is acknowledged and accepted as beyond government control.[89] This difference could explain the variation regarding heart transplantation for Down's patients.[90] In 1996, a patient with a relatively minimal impairment of intellectual ability was refused heart transplantation by Harefield Hospital because of her 'other problems' which included a suppressed immune system. This is actually the clinical situation required for successful transplantation. The BMA has now expressed its opposition to such discriminatory practices: 'incapacitated patients and those with learning difficulties should have the same opportunity to access scarce resources'.[91] However, a nine year old girl with Down's syndrome was recently refused a heart transplant allegedly because her 'quality of life is not good enough'.[92] Such discrimination on the part of doctors seems far worse than that shown by families who wish to attach racist conditions to donor organs.[93]

Particular difficulties arise with children. In the case of Laura Davies,[94], parental preferences and medical opinion concurred although the initially-applauded decision became increasingly subjected to criticism.[95] In *Re T*[96], parental preferences clashed with medical opinion, the courts eventually favouring the parents.[97] In a third case, a 15 year old girl was given a heart transplant against her wishes.[98] 'Best interests', child autonomy, family values and medical determination have varying degrees of influence in such situations.

3.2.2 The chronically ill and the withholding of dialysis

Kidney failure is sometimes reversible but often is a terminal event in the aging (dying) process.[99] In which case, providing dialysis[100] merely extends the dying process and is medically futile since eventually the patient will undergo complete failure of other organs. However, if the patient is considered simply in terms of the immediate problem, kidney failure, dialysis is actually very effective.[101] The costs form a substantial amount of any health budget.[102] Dialysis cannot readily be seen as too burdensome or invasive so some purchasers limit

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[88]Ibid.

[89]However, the BMA has ended its opposition to an 'opting out' system: Anon. BMA starts debate on presumed organ donation. *BMJ* 1999;**318:**131.

[90]*Cutting Edge: A heart for Jo.* Channel 4 Television September 1996. In contrast, the programme showed an American woman, with the same condition but less able to express herself, who had had a successful heart transplant.

[91]BMA Medical Ethics Committee. *Withdrawing and Withholding Treatment* 1998 BMA, London at p12.

[92]Rogers L. Hospital refuses new heart to Down's child. *The Sunday Times* 25 July 1999.

[93]Wilkinson P, McGrory D. Union officials leaked racist donor request. *The Times* 8 July 1999 (reporting a 'whites' only request). McGrory D. Surgeons ignored racist conditions. *The Times* 9 July 1999 (reporting an 'Asian only' request).

[94]An infant who had been born with a congenital condition incompatible with life and who underwent multiple organ transplantation in the U.S.A.

[95]*Weekly World News Digest* December 23 1993. Article reporting her death on 11 November 1993 following a stroke eight weeks after a second multiple organ transplant operation which had involved the transplantation of seven organs.

[96]*Re T (a minor)(medical treatment)* [1997] 1 WLR 242. His parents refused the option of liver transplantation knowing that a successful treatment could lead to life expectancy being measured in years rather than months without transplantation.

[97]A more detailed analysis of these two cases will be undertaken later. It is worth noting the stress placed by the court upon the fact that the parents were 'health professionals' indicating that they had greater authority to challenge the medical model than other parents would have had in the same situation.

[98]*Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097. This case will be discussed later.

[99]In other words, due to ageing, the patient is entering into multiple organ failure and the heart will also be weak, the liver function poor etc. Alternatively, the patient has developed kidney failure as a result of widespread terminal cancer which would come under the same categorisation as being part of the dying process.

[100]Dialysis is a technological process by which the toxins, normally eliminated by the kidneys, are removed from the blood stream. If these toxins are not removed, death will occur within a few days. Sometimes it is carried out in hospital taking several hours two or three times a week. Other types of dialysis are now available for use outside hospital. One is Continuous Ambulatory Peritoneal Dialysis (CAPD) where the patient is dialysed by means of a special apparatus attached to the waist during the day and can carry on a normal life whilst dialysis being performed. There are greater risks of infection attached to CAPD and it is not suitable for all patients. Personal Communication.

[101]Medical audit will assist in the appropriate classification of patients. However, it may be that at the time the patient develops renal failure, there is no knowledge available to the clinician as to why it has developed or whether the patient has other co-morbid conditions so dialysis often will be implemented and withdrawn later. The discussion regarding withdrawal is found in the next chapter.

[102]Devettere, op cit n41 at p187, reports that in the USA costs will have risen to $10 billion by the year 2000 (to treat 300,000 patients).

access to dialysis by introducing age-limits on funding.[103] Such arbitrary rationing ignores individual prognosis and seems discriminatory.[104] Attempts have been made to establish the 'cost-utility' of different treatments for patients in end-stage renal failure.[105] Gudex suggests these are unsuccessful because of 'national differences in experience of illness...age differences,...different guidelines regarding acceptance into treatment programmes and the variability of the quality of data employed.[106]

Rationing by providers is more secretive - the public assumes only inappropriate treatment is withheld.[107] Most doctors withhold dialysis from permanently unconscious patients.[108] Others suggest that fear of litigation would make them provide treatment they felt inappropriate.[109] A recent Canadian paper evaluated refusal of dialysis decisions at one centre - most were elderly patients with 'poor functional capacity and multiple complications'[110] and female.[111] A quarter of referrals were rejected despite adequate resources, most dying within six months.[112] Lowance suggests that chronologically or physiologically old patients with a predicted life expectancy of under 2 years should be advised not to have dialysis.[113] Hirsch's 'guidelines' which he advocates should be applied flexibly, indicate 'advising'[114] non-acceptance of dialysis if the patient is demented, has metastatic cancer, end-stage disease of other organ(s) or the need to sedate/restrain the patient during dialysis.[115] The underlying philosophy is that treatment is inappropriate if it will only have short-term effectiveness. His approach is inconsistent however. He comments, '(w)e have always discussed our reasoning with the patient and family, and have always assured ourselves that **any decision not to offer dialytic support** is understood'[116] suggesting his patients are not offered choices after all. The debate about withholding treatment is ill-served if fellow professionals and the public are misled.

3.2.3 The patient with cancer

Public outcry has followed the withholding of treatment/drugs for cancer patients.[117] Research focuses on

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[103]For instance, Wiltshire HA announced in 1997 that it would not purchase dialysis treatment for patients over 65 years - see Chapter 3. Block contracts impliedly acknowledge that rationing is necessary.

[104]One of the aims of the NHS reforms under the Labour administration is to create a 'national' healthcare system which eliminates such regional variations: *A First Class Service: Quality in the NHS* 1 July 1998 (HSC1998/113 NHS Executive, Leeds) at para 1.8.

[105]Gudex CM. Health related quality of life in end-stage renal failure. *Quality of Life Research* 1995;**4**:359-366. Gudex examined the health related quality of life (HRQOL) of 705 patients and found that estimates of HRQOL and cost per QALY 'should not be used out of context or without a careful study of the life domains they are based on and the way in which data were collected and processed'.

[106]Ibid, at p365.

[107]There is no central agency in the UK compiling data on refusal of dialysis to serve as a means of informing future decisions about whether to treat an individual patient or not. This could be something the NICE includes as part of its remit when it examines dialysis.

[108]In such patients, the decision to withhold could be seen as recognising the fact that, following the irreversible brain damage, the patient was now moving from a stable, otherwise healthy condition, to the dying process. Moss reports a survey in the U.S.A. which revealed that 83% of centres would withhold dialysis although one doctor said that, if requested, he would provide dialysis to such a patient. Moss AH et al. Variation in the Attitudes of Dialysis Unit Medical Directors Toward Decisions to Withhold and Withdraw Dialysis. *J.Am.Soc.Nephrology* 1993;**4**.2:229-234 at p322.

[109]Moss AH, op cit n109, at p233. This raises the same concerns as artificially ventilating anencephalic babies. The legal issues will be considered in a later chapter.

[110]Hirsch DJ et al. Experience with not offering dialysis to patients with a poor prognosis. *Am.J.Kid.Disease*1994; **23**,3:463-6 at p463.

[111]Ibid, at p464. There was insufficient information to assert bias. It may simply be that the patients referred were elderly and women have a longer life expectancy.

[112]Ibid.

[113]Lowance DC. Factors and guidelines to be considered in offering treatment to patients with end-stage renal disease. 1993 *Am.J.Kid.Disease* **21**:679-683.

[114]Hirsch DJ, op cit n111, at p465.

[115]Ibid, at p466.

[116]Ibid, at p465. My emphasis.

[117]Perhaps one of the better known cases being that of 'Child B': *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.

'cures' and better predictors of treatment outcomes.[118] Chemotherapy drugs are extremely expensive.[119] The NHS saves money by relying upon free provision of trial drugs and the willingness of patients to gamble that they are in the group receiving the new generation treatment.[120] Some patients opt for non-treatment.[121] However, the patient's right to exercise autonomy may be challenged by doctors.[122] How quickly someone is treated depends on how their need '*as perceived by the doctor*' is rated.[123] This may depend on 'age, general health and usefulness to the community'.[124] Treatment may be withheld because of the doctor's subjective opinion rather than an objective assessment of the clinical benefits of treatment.[125] Rationing by age[126] or refusal to fund occurs.[127] Some countries allegedly over-treat to avoid litigation on grounds of negligent practice.[128] Cochrane was one of the early exponents of audit and research into effectiveness of treatment.[129] However, a rapid political shift towards evidence-based medicine could mean that, in order to comply with deadlines, mistakes or fabrications of results occur.

3.2.4 The patient requiring artificial nutrition and hydration

Following *Bland*[130], artificial nutrition has now been classed as medical treatment. However, *Re R* [131]suggests it differs from other treatments and withholding it is not viewed as favourably as withholding antibiotics.[132] Most doctors seem to consider it appropriate to withhold treatment if the patient is dying and evidencing no

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[118]The University of Hull has developed a computer program which can predict how long a cancer patient will live with 90% accuracy: Dobson R. Program predicts cancer deaths. *Sunday Times* Medicine 28 September 1997. Such information can be invaluable in helping the medical team and the patient to decide which treatment model to adopt.

[119]McNeil B. Implementing advances in medical technology: the American view. *J.Roy.Soc.Med.* 1995; **88** (Supp26):26-7. She reports that in one Boston hospital, the new 'biotech' drug, Ondansetron, used to combat nausea associated with chemotherapy thereby improving quality of life, now accounts for 6% of the total drug budget. Cancer drugs are generally expensive as the drug companies seek to recoup development costs in the short time available as sole licensees.

[120]The number of patients in such trials is set to double: Secretary of State for Health. *The NHS Plan: A plan for investment a plan for reform.* (Cm 4818-1) 2000 The Stationery Office, London at para 14.7.

[121]Or less radical treatment than the consultant recommends. For instance, a patient with breast cancer may prefer a 'lumpectomy' to a radical mastectomy, or chemotherapy alone, or opt for alternative medicine rather than conventional. Surgery may be the option which is most likely to produce the greatest quantity of life overall but alternatives such as radiotherapy for cancer of the larynx might be more acceptable to some patients rather than losing the ability to speak. McNeil BJ et al. Speech and survival: trade-offs between quality and quantity of life in laryngeal cancer. *NEJM* 1981;**305**:982-7.

[122]Morrison RS et al. When too much is too little. *NEJM* 1996; Dec 5:1755-9 at p1757. Morrison discusses an American case where the patient opted for non-treatment of lung cancer with an associated brain tumour yet, following epileptic seizures caused by the increased brain tumour, the patient spent his last 47 days in an acute hospital undergoing a lung biopsy, 3 brain scans, insertion of a naso-gastric tube and a gastronomy tube (a feeding tube that goes directly into the stomach through the abdomen) and was tied to his bed for 29 days to prevent him pulling out the tubes.

[123]Stoll BA (Ed) *Ethical Dilemmas in Cancer Care* 1989 MacMillan Press Ltd, Basingstoke at p17. His emphasis.

[124]Ibid.

[125]Criteria used include 'whether they were breadwinners, whether they could cope with the financial and social after-effects of their treatment, their home circumstances and the number of years of active life the procedure would give them'. Stoll op cit n124, at p18.

[126]Stoll also reports that in Stockholm, a proposal was made to withhold radiotherapy from patients over 70 years with certain cancers in order to expedite treatment for younger patients but had to be abandoned following public outcry. Stoll op cit n124, at p19.

[127]Clinically-effective cancer drugs are being withheld from patients because of the costs. Laurence J. Timid doctors fail to give heart patients the best drugs. *The Times* 27 August 1996.

[128]In the U.S.A. in the 1980's, 'adjuvant' cytotoxic chemotherapy was routinely given after first line surgical treatment for breast cancer yet this was not standard practice in the UK. The reason for its popularity in the States is suggested as because of the greater tendency to practice 'defensive medicine' there. It is possible that the dismissal of the use of adjuvant chemotherapy is an example of jingoism since, if a practice has been widely adopted by a particular country, this might indicate a belief that some benefit was accruing to the patient.

[129]Cochrane AL. *Effectiveness and efficiency.* 1972 Nuffield Provincial Hospitals Trust, London. The Cochrane database has been doing this for several years now with regard to cancer treatments.

[130]*Airedale NHS Trust v Bland* [1993] AC 789.

[131]*Re R (Adult: Medical Treatment)* [1996] 2 FLR 99.

[132]See the conclusions on this point in the BMA document, *Withdrawing and Withholding Treatment: A consultation paper from the BMA's Medical Ethics Committee* 1998 BMA, London at p22 (discussed more fully later).

signs of hunger or thirst.[133] However, inappropriate withholding seems tantamount to inhumanity.[134] The media calls it 'backdoor euthanasia' when maintaining fluid balance through nasogastric tubes is withheld in the case of stroke patients over a certain age.[135] These concerns led to attempts to legislate against such practices but politicians seem wary of tangling with the BMA.[136]

3.3 Outcome of Reduced Quality of Life

3.3.1 Reproductive Issues

Reproductive issues regularly tax medical ethicists and lawyers alike.[137] The right to do what one wishes with one's own body is constrained by Parliament, the judiciary, doctors and healthcare purchasers. How and where a woman gives birth is constrained by resources, the medical profession and the courts.[138] A woman's desire to control her fertility is constrained by doctors/resources and her freedom to choose permanent sterility or abortion is limited.

Infertility, a problem of both sexes, is potentially treatable but NHS provision is patchy and inequitable. The Human Fertilisation and Embryology Act 1990 restricts the availability of assisted reproductive services.[139] Accessing treatment is governed more by wealth than most other medical interventions. Most provision is through the private sector which can introduce inappropriate financial motives.[140] The Glover report identified as the 'standard' case, the infertile married couple but recognised that others may seek assistance: unmarried couples; single persons and homosexual couples.[141] The report queried whether IVF was 'medical treatment' since it merely circumvented the problem not cured it.[142] Whilst not wanting to make 'the morality or availability of in-vitro fertilisation (IVF) depend on a definitional point' it recognised a difference between

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[133]Lennard-Jones has recently made several recommendations regarding artificial nutrition and hydration. Number 5 states 'If the plan is to provide compassionate care for relief of symptoms during the terminal phase of illness...fluid through a tube should be given only if it is to relieve thirst'. Lennard-Jones JE. Giving or withholding fluid or nutrients: ethical and legal aspects. *JRoy.Coll.Phys.* 1999;**33:**39-45.

[134]A doctor was recently disciplined by the GMC for ordering food supplements to be stopped. Horsnall M. GP Guilty of letting elderly patient starve. *The Times* 26 March 1999. The referral to the GMC was reported two years before: Anon. Woman dies two months after food withdrawal. *BMJ* 1997;**314:**1503. This topic has been the subject of media interest and relatives have expressed concern and distress over the decision to withhold what some consider to be basic care. Horsnall M. Police check hospitals over 'backdoor euthanasia'. *The Times* 6 January 1999; Hornsnall M, Foster P. Euthanasia claims sow doubt in families' minds. *The Times* 6 January1999 and Hornsnall M. Euthanasia opponents want oath restored. *The Times* 7 January 1999.

[135]Death will occur very rapidly if adequate hydration is not maintained when the brain has received a major assault as in a traumatic head injury or stroke.

[136]Ann Winterton introduced a private members bill, Medical Treatment (Prevention of Euthanasia) during the parliamentary session from 1999 - 2000 but aggressive lobbying of MPs by the BMA resulted in its failure.

[137]There have been several cases involving the sterilisation by hysterectomy of women with learning disabilities and recently, one request for a man with Down's syndrome to have a vasectomy: *Re A (Male Sterilisation)* [2000] 1 FLR 549.

[138]Whilst the competent woman's right to refuse Caesarian section has been upheld (*R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728), the woman deemed incompetent 'due to the throes of labour' (*Rochdale Healthcare (NHS) Trust v C* July 3, 1996 Unreported) is vulnerable to coercion. See the discussion in a later chapter.

[139]Again, different countries have different approaches. For instance, Canada's Royal Commission, reporting in 1993, has recommended that only women who have blocked Fallopian tubes should be able to have in-vitro fertilisation. Devettere, op cit n41 at p277.

[140]The recent case of the sixty year old woman, Elizabeth Buttle, who is said to have 'lied about her age' to the private clinic which treated her 'infertility' by administering drugs to reverse her menopause and IVF treatment leading to the birth of a live child which she initially claimed to be a 'natural birth' has outraged many who question why this woman was able to obtain treatment which is not available to many 'ordinary' couple: *BBC News* 21 January 1998. (In a similar case, an American widow aged 63 also lied about her age and received embryo(s) from donated eggs and sperm also leading to a live birth: Internet source: http://itssrvl.ucsf.edu). An Italian infertility expert has stated that he intends to create the world's first human clone. Farrar S. Maverick fertility expert plans first human clone. *Sunday Times* 25 October 1998.

[141]Glover J and others. Ethics of New Reproductive Technologies: The Glover Report to the European Commission. 1989 Northern Illinois University Press, DeKalb, Illinois at p24.

[142]Ibid, at p45. In this sense it does not differ from the way that spectacles and hearing aids act.

wanting IVF for 'social' reasons[143] and to prevent genetic disorders.[144] It approved assessing candidates for parental suitability since those 'whose help is sought may have some responsibility for the consequences of their assistance'.[145] The underlying philosophy aims to protect future children from abuse but it is questionable whether such propensities can detected in advance or whether assisted parenthood should be treated differently from natural.[146] It gives doctors powers without training in their use, over issues not obviously their responsibility. It can lead to bias regarding class, education, family set-up, previous criminal convictions etc.[147] If future potential antisocial behaviour is a reason to withhold treatment, doctors should withhold methadone from drug addicts. If society is prepared to protect the interests of a person who has not yet been born,[148] or may not be born, by denying him/her the possibility of life because IVF is withheld, why does it tolerate the abuse of future victims of the criminal drug addict, who are real and present persons? It is surely only appropriate to withhold IVF on the same grounds as other treatments.[149] If procreational ability is classed as a 'fundamental interest' to be protected, just as 'the services of the police should not depend on the citizen's ability to pay',[150] IVF would become a 'basic good' available to all.[151] Then the state could arguably be in breach of an obligation to assist the infertile which could mean the NHS should be making IVF freely available.

Giving birth is not always straight-forward. Not all maternity units can offer Caesarean sections in the event of an emergency.[152] Such units try to predict 'high risk' pregnancies and refer them elsewhere but unexpected complications may occur at a stage in labour when it is impossible to transfer the mother.[153] Maternity care is generally purchased in 'blocks' so 'trade-offs' between public demand for local maternity care and the need to prevent harm are evident.[154]

Other women wish to control their fertility but some religions consider contraception immoral and laws reflecting such views place a huge burden upon women.[155] Hospitals sponsored by religious organisations, may prevent 'a woman in poor health (who) requests in good faith a tubal ligation during a Caesarean section' from

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[143]For instance, so a couple can have a child that is biologically theirs or a professional woman, without a partner, can have a 'designer' baby. Recently, two homosexuals became the parents of twins through the use of donor eggs and a surrogate mother. O'Connell A. Gay parents of twins make legal history. *The Times* 13 December 1999.

[144]Glover, op cit n142, at pp45-6. For instance, some inherited conditions, like muscular dystophy, produce their disabiling effects only in male children and the use of IVF to enable only female embryos to be implanted can avoid this although the females will still possibly carry the recessive gene and so be carriers.

[145]Glover, op cit n142, at pp49-51 at p49.

[146]One case where the potential for harm to the child both in-vitro (foetal alcohol syndrome) and afterwards (possible neglect or abuse) was detected by the use of tests following comments with the patient which lead the doctor to suspect alcohol addiction was *R v Ethical Committee of St Mary's Hospital (Manchester), ex parte H* [1988] 1 FLR 512. The patient also had convictions for prostitution and running a brothel and had been deemed unsuitable to adopt. The doctor did not disclose to the patient the true reason for withholding IVF which could be interpreted as preventing the patient from accessing help and modifying her behaviour. The patient's application for judicial review was rejected.

[147]Glover also questions whether society 'has an interest in preserving the traditional family' and, if so, if this is 'in conflict with the desire not to discriminate against potential parents who are single or homosexual'. Glover J and others. *Ethics of New Reproductive Technologies: The Glover Report to the European Commission.* 1989 Northern Illinois University Press, DeKalb, Illinois at p52.

[148]For a discussion of some of the issues relating to whether society owes any responsibility to those who may or may not live in the future, for instance, in terms of saving world resources, see, Fotion N, Heller JC (Eds): *Contingent Future Persons - on the ethics of deciding who will live, or not, in the future.* 1997 Kluwer, Dordrecht.

[149]Very little is actually known about the causes of infertility since those working in the field have concentrated on ways to circumvent the problem not cure it. The 'take home' baby rate is very low and little is known as to why some couples are more likely to succeed than others. Medical audit could provide useful information.

[150]Glover J and others. *Ethics of New Reproductive Technologies: The Glover Report to the European Commission.* 1989 Northern Illinois University Press, DeKalb, Illinois at p87.

[151]Loc cit.

[152]Foetal distress is a condition where, for various reasons, the oxygen supply to the baby becomes impaired and the baby is at high risk of brain damage as a result.

[153]The outcome for babies born in such circumstances is often poor as a result. One example is that of *Bull v Devon AHA* [1993] 4 Med LR 117.

[154]This situation is liable to continue with the introduction of PCG Commissioning even though logic would suggest all births should take place in hospitals with all the necessary facilities to cope with emergencies.

[155]For instance, Eire, a predominantly Catholic country, where various legal actions have challenged the restrictions on the freedom of information about contraception and abortion. Most Moslem countries also consider abortion and contraception to be criminal acts or punishable under their religious code. Lack of access to contraceptive information and treatment has been blamed for Britain's teenage pregnancy rate even though this has not been due to religious prohibitions.

having that procedure carried out so she has to undergo sterilisation later at another hospital.[156] Recently the right to reproduce of mentally-handicapped vulnerable women has been protected by using contraception rather than sterilisation[157] although withholding sterilisation could expose them to side-effects they cannot appreciate and whether they would be allowed to continue an accidental pregnancy is doubtful.[158] Occasionally, pregnant women are rendered permanently incompetent during pregnancy and some doctors may advise aborting the foetus whereas others will use the woman as an incubator.[159] Such recommendations seem based more on the doctor's personal beliefs than clinical data.

3.3.2 Other conditions

Many patients have early symptoms enabling detection of cardiac problems before cardiac arrest.[160] Friedman examined the 'vexing problem' of whether to fit patients with 'pacemakers'[161] rather than treating with drugs.[162] He concluded that costs would be so high only a 'carefully selected subgroup of survivors of myocardial infarction who are at highest risk for sudden death' should be treated.[163] Other treatments may be restricted.[164] Often the decision is supported by clinical evidence as to the effectiveness of treatment but national variations exist.[165] Mentally-ill patients may have treatment withheld because experts disagree over fundamental issues such as what constitutes mental illness;[166] diagnosis and treatability.[167] Patients may have concurrent physical and mental illness affecting the approach taken by both patient and doctor. 'Severe' mental illness is prioritised[168] but this means different things to different referral agencies.[169] If not 'severely' ill places for treatment are limited. Consequently, some patients await treatment so long their condition deteriorates with tragic consequences for themselves or others.[170]

Occasionally, patients request medical treatment which is seldom or never used in this country.[171] Chemical castration has been requested by prisoners but the BMA has concerns about unknown long-term side-effects and the potential to affect the genetic material of the sperm which could produce congenital abnormalities in

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[156]Devettere, op cit n41, at p271.

[157]Recent case law has recognised the invasive nature of sterilisation procedures: see discussion later in this thesis.

[158]Complications such infertility may follow as a result of having a termination and 'strokes' caused by blood clots have recently been recognised as a potential side-effect of the 'pill'.

[159]See, for example, the case of *Re AC* 533 A2d 611 (DC App. 1987). See also: English R. This is the little girl born to a woman in a coma. Behind her smile is a story of feuding and heartache. *Daily Mail* 8 April 2000.

[160]Waiting lists mean that some patients die awaiting diagnostic procedures such as angioplasty which in other countries would be carried out within hours or days of symptoms first occurring. One such patient, died the day before his angiogram appointment after a six month wait: Rogers L, Prescott M. The Human Cost of Waiting Lists. *The Sunday Times* 4 June 2000.

[161]Properly called implantable cardioverter-defibrillators.

[162]Friedman PL, Stevenson WG. Unsustained ventricular tachycardia - to treat or not to treat. *NEJM* 1985;**335**,26:1984-5 at p1985.

[163]Ibid. In 1985, the cost would be over $1 billion annually excluding aftercare.

[164]For instance, hip replacement and cataract operations are not available to everyone since costs and patient age or other pathologies may be considered. Not all hospitals treat childhood deafness caused by middle ear infection with antibiotics or surgical insertion of grommets.

[165]See Wennberg's call for action to address the 'phenomenon of geographic variation in the use of medical services and its connection to differences in practice style between physicians or 'medical opinion''. Wennberg JE. The Agenda for Outcomes Research. In: *Appropriate investigations and treatment in clinical practice*. Ed: Anthony Hopkins. 1989 Royal College of Physicians, London pp77-90 at p77. The government is intending to address such inequalities as already discussed: *The New NHS* (Cm 3807) December 1997, para 8.5 ii: 'Fair access. To recognise that the NHS contribution must begin by offering fair access to health services in relation to people's needs, irrespective of geography, class, ethnicity, age or sex'. Also, para 8.5 iii: 'Effective delivery of appropriate healthcare. To recognise that fair access must be to care that is effective, appropriate and timely, and complies with agreed standards. For example, increasing provision of treatments proven to bring benefit such as hip replacements...'

[166]For instance, the debate over whether anorexia really exists or whether it is merely evidence of 'obliging' behaviour by certain young women.

[167]Adding to this is the problem that there is no clear agreement as to whether patients should be cared for by the specialist mental health services, primary care services, social services, prison service or merely just a housing agency: Muijen M. Mad, bad and dangerous to know. *Health Service J.* 18 July 1996 p25.

[168]NHS Executive. Priorities and Planning Guidance for the NHS 1997/98 (prioritisation for specialist services) Dept of Health, Leeds. Also, The Review of Purchasing of Mental Health Services by Health Authorities in England 1996 Dept.of Health.

[169]Muijen M, n167, loc cit. The different referral agencies include hospital consultants, GPs, social workers, etc.

[170]For instance the murder of Jonathon Zito by Christopher Clunis. See: *Clunis v Camden and Islington Health Authority* [1998] 2 WLR 902.

[171]There is no recorded instance of surgical castration being carried out in this country although it has been performed abroad.

any children born later.[172] Treatments such as female circumcision are considered in Western society to be mutilation and abusive of children.[173] Society's interest in preventing abuse outweighs parental wishes or cultural requirements. Another controversial treatment is the use of plastic surgery to correct the characteristic facial features of Down's Syndrome children.[174] The discomfort and risks of treatment are offset against the benefits of better integration into society. The BMA points out that such treatments are 'procedures which might reflect the priorities of other people rather than the patient' and suggest, probably correctly, that such treatments should require prior judicial approval.[175] With this, the BMA seems prepared, for once, to question the extent of medical power. A retired Consultant Paediatrician has called for such 'corrective' plastic surgery on children too young to consent for themselves to be 'outlawed' like female circumcision.[176]

A different example is of the suicidal patient requiring treatment following an overdose or the injured drunken driver. S/he may still be conscious and resisting attempts to help. It seems apparent in such a situation that treatment cannot ethically be withdrawn just because of resistance but the underlying basis for this conclusion is less apparent.[177] Is it because the patient is considered incompetent to refuse treatment or is it an emergency 'life or death' situation and consent is deemed unnecessary? Is it because paternalism[178] is acceptable in such circumstances or is there an overriding duty to attempt to save life? Is self-harm/suicide so morally wrong that overriding personal autonomy is permissible? This latter view, grounded in 'concern...for their moral character'[179] could explain the resistance to euthanasia.[180] Or is it that respect for persons means recognising that the reasons influencing the behaviour of the person may be beyond autonomous control and when this is so, there is an obligation to provide treatment, by force if necessary, until these temporary factors are no longer influential? Harris suggests that respect for autonomy means recognising that each individual is 'valuable'[181] whether they are depressed, drunk or drugged therefore concern for their welfare and respect for their wishes will be shown by those caring for them. However, trying to provide treatment may place healthcare professionals at risk of violence.[182]

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[172]BMA. *Medical Ethics Today: Its Practice and Philosophy.* 1993 BMJ Publishing Group, London at p112. This indicates a reliance upon the scientific (outcomes) model of decision-making. The government has accepted, in such situations, that this is more appropriate than the patient-preference model. However, it may be better to withhold treatment as a matter of principle since such patients may refuse to continue treatment after early release and so pose a greater public threat than if they remained imprisoned which introduces the possibility of a social welfare model.

[173]It is proscribed by the Prohibition of Female Circumcision Act 1985. A critique of the Western world's refusal to carry out female 'circumcision' has pointed out that the West does impose its notion of what is 'normal' when partial clitorectomies are performed on female children with enlarged 'penile-like' genitalia. Harvey K. A Mother's Dilemma *Pioneer Planet* 4 March 1999, www.pfc.org.uk. The author of this thesis has had personal communication from several midwives caring for Somali women that having cut the woman to allow the baby to be delivered, they are intimidated by the partners, who insist on being present, into stitching her up as tightly as before.

[174]This issue is explored in a television documentary, *Changing Faces* 24 November 1998, ITV, London and Hinsliff G. The Down's Dilemma *Daily Mail* 5 June 1997.

[175]BMA. op cit n173, at p76. If the parents wished their child to look more 'exotic', it is doubtful a doctor would rely, as presently, solely on parental consent. There are no recorded instances of the court's approval being sought prior to such surgery and since such surgery is being carried out in this country, those performing it are relying upon parental consent being sufficient. Whilst this may be acceptable for surgical correction of 'bat ears' it is questionable.

[176]Jones RB. Parental consent to cosmetic facial surgery in Down's syndrome. *J.Med. Ethics* 2000;**26:**101-102.

[177]In fact, the accepted stance in Accident and Emergency departments in this country seems to be that the patient's competence must be assessed and if the patient appears competent, the staff are powerless to render assistance until the patient agrees. Sometimes, a psychiatrist will be called in to provide an 'expert' opinion. This constitutes a positivist interpretation of the law regarding consent to treatment as found in *R v St Georges NHS Trust, ex parte S* [1998] 2 FLR 728. Legal issues regarding treatment refusal will be addressed in a later chapter.

[178]Which can be defined as a belief that the will of others can be overridden , regardless of their wishes, if the person with authority considers it right to do so.

[179]Harris J. Professional responsibility and consent to treatment. In: Hirsch SR, Harris J (Eds). *Consent and the Incompetent Patient: Ethics, Law and Medicine.* 1988 Gaskell, London pp37-53 at p40.

[180]The question of euthanasia is so complex and troubled that it cannot be addressed in any depth in this thesis although an awareness of the various views pertaining to it will be assumed and reflected in the few comments specifically mentioning the subject.

[181]Harris J, op cit n180, at p 39.

[182]The government has recently announced a 'Zero Tolerance' campaign to reduce violent attacks upon NHS staff. Department of Health. *We don't have to take this: Resource Pack.* L20/002 November 1999 DoH, Wetherby.

3.3.3 Treatments for the Benefit of Others

Sometimes treatment is given which carries no physiological benefit for the patient. Siblings or parents may donate kidneys, liver/lung lobes or bone marrow to their relatives.[183] Their quality of life will be impaired, at least short-term, but society currently considers such sacrifices noble.[184] It may even be a social duty.[185] Another situation where treatment carries risks for one but benefits for another is where the use of Caesarian section to deliver a baby with spina bifida reduces disability.[186] The question arises, is there any difference between carrying out a Caesarian section, with its risks to the mother, in order to prevent a 'normal' baby being brain-damaged or to reduce the level of handicap in an 'abnormal' baby? Would the woman's refusal be considered more culpable in one case than the other?[187] Certainly, a negligent failure to offer a Caesarian in such a case could be actionable.

3.4 Empirical Research Analysis

This section analyses the responses given by the eighty-five consultants interviewed to the following questions[188]:

> *Regarding the individual patient, when deciding to withhold or withdraw certain treatments, what sort of criteria do you use and which criteria should not be used?*
>
> *Who should be involved in the decision to treat/not to treat a particular patient?*
>
> *Do you think relatives should have a say?*

Caution has to be exercised regarding the interpretation of the responses. There is a danger that what happens in practice differs from what is said to happen. In interpreting this data I have attempted to identify discrepancies within individual consultant's accounts as well as between consultants.

3.4.1 Criteria used in deciding to withhold certain treatments

Evaluating the responses enabled a number of criteria, utilised either singly or jointly, to be identified. Sometimes these were implied in what was said rather than used as classifications of approach by the

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[183]The reasons being the shortage of dead donors and also because genetically related donated tissue is less likely to be rejected by the recipient even when an equally good match with an unrelated donor exists for reasons the medical profession as yet do not fully understand. In several instances these proposed transplants have been the subject of court decisions and will be discussed in more detail later.

[184]Of course, it may be that societal views could change and if the living donor later develops problems that are attributable to his/her 'fault' in being 'stupid' (for instance, if having donated a kidney, the donor later develops renal failure) this may be considered a reason to withhold treatment from him/her. Little is actually known about the long-term effects of being a living donor. A critique of how such decisions are made, particularly when incompetent patients are the potential donors, is in a later chapter.

[185]For an interesting discussion of this point see Mason JK, McCall Smith, Laurie GT. *Law and Medical Ethics* 5th Edn. 1999 Butterworths, London at pp345-6.

[186]See: Davis A. 'All babies should be kept alive as far as possible'. In Gillon R (Ed). *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp629-641 at p638. The study she quotes from found that children delivered by caesarian section were less likely to have severe paralysis (Luthy DA et al. Cesarean section before the onset of labor and subsequent motor function in infants with meningomyelocele diagnosed antenatally. *NEJM* 1991; **324**:662-6).

[187]Unless the competence of the woman is to be called into doubt, the law, as it currently stands, will support even 'irrational' refusals of treatment. There will be a fuller discussion of the issue of enforced treatment in a later chapter.

[188]A list of the consultants, maintaining confidentiality, can be found in Appendix A. The consultants were based at four different hospitals (A - D), and were from a variety of specialties. A descriptor of the hospitals, maintaining confidentiality, can be found in Appendix B.

consultants themselves. Some consultants considered certain criteria appropriate to use which others rejected as inappropriate resulting in overlapping responses to the first question. The data will be analysed utilising themes based on the following criteria:[189]

Criteria which were considered appropriate to use included:

a) treatment clinically ineffective

b) the patient's quality of life

c) balance of burden greater than benefit

d) wishes of patient (including those expressed in advance directives)

e) the patient's social circumstance

f) financial costs

g) timing costs

h) burden on the family

i) burden on healthcare staff

j) the patient's age

Criteria which some consultants rejected as inappropriate to use included:

a) financial costs

b) wishes of relatives

c) merit of the patient

d) patient's responsibility for illness

e) the patient's age

3.4.1.1 Effectiveness of Treatment

The clinical effectiveness of treatment was cited by most of the consultants as the starting point for deciding whether to treat or not though gaining patient acceptance of this could be difficult. Typical comments included:

> *I never withhold appropriate medical treatment.* D10

> *My two criteria for giving treatment are: will it cure or will it relieve suffering.* A24

> *One looks at the disease process. Not necessarily...age, I've just finished operating on an 87 year old.* D2

> *We do not attempt to resuscitate someone who is partially or totally decapitated; is decomposing or who has rigor mortis.* C16

> *If someone is manic-depressive or schizophrenic and they ask for psychotherapy I say no because it*

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[189]Some criteria could fit into more than one theme but the themes selected are: Effectiveness of treatment (which could have included patient age and/or present quality of life); Quality of life (which could have included the Balancing of Benefits and Burdens); Balance of Benefits and Burden; Patient Wishes; Social Circumstances (which was taken to include the burden on carers); Resource Implications (which was taken to include financial costs, timing costs and burden on healthcare staff but could also have included age as a restricting factor on resource allocation) and finally, Age.

could lead to a recurrence of their psychosis. A28

The predicted outcomes of treating were important in deciding whether to withhold treatment but a difficulty many faced was insufficiency of accurate data. Consequently, several indicated that although they believed, as a result of previous experience, a certain patient or condition would not be helped by a particular intervention, they felt compelled to offer the chance of treatment:

The more holistic physicianary approach is to say, this is the pre-terminal event in someone at the end of their life and it should be treated as such. D9

If they've got a greater than 50% chance of not surviving 30 days from surgery, I would view that as grounds for not offering that treatment. A17

One of the criteria...laid down to us recently was that people had to have a prognosis of about a year, at least a year. Nobody can tell who has a prognosis of a year. A10

I would not rule out anything for anybody... (but) there is a temptation to present the available options as the recommended ones. C1

Sometimes, experimental treatment would be used as a 'last-ditch' attempt to save life[190] posing risks which may not be fully understood at the time. The few who mentioned this did not clarify whether they consider the decision was theirs alone or whether the patient, if competent, should be involved.

In certain instances one decides to use either experimental drug therapy or drugs that have not been of strictly proven value. B2

One consultant mentioned gender reassignment indicating that a reason for not treating could be because patients are dissatisfied with even the best achievable results. This indicates a conflict between patient expectations and surgical reality and whether a professional should perform surgery which they consider is currently unsatisfactory.

We don't do them here. I've been involved in the past but they are never happy people, I've never known one that actually feels that that was brilliant. They always want something more, very dissatisfied, and I personally feel as a surgeon I don't like that. B10

Smoking was mentioned by a few consultants as a reason to withhold treatment, not to punish, but because the evidence is that outcomes are poor:

You're not denying treatment, you're perhaps offering them a management strategy that is different

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[190]Proposed revisions to the Helsinki Declaration included (Draft paragraph 7): 'In the treatment of a sick person with a progressive, disabling or potentially fatal disease for whom existing therapy is either not effective or not available, the physician should be free to recommend use of a new diagnostic and therapeutic measure, if in his or her judgment it offers hope of saving life, re-establishing health or alleviating suffering. Employment of such interventions, commonly called 'compassionate use' and formerly called 'clinical research' is not properly regarded as research.' *Bull. Med. Ethics* 1999;**146:**3.

from their perception of what they're going to have...I have a couple...whom I've said I'm not going operate on them as I think they are too overweight and they smoke. A18

If they smoke they don't have treatment, and there's no question about that. A25

Some consultants seemed more comfortable with the concept of withholding treatment than others. Sometimes it seemed appropriate to start treatment and review later when more evidence was available[191]:

If I think it (dialysis) is not going to make any improvement, and it's very difficult to predict that so I usually tell them - that I'm not certain it is going to make any difference; these are the difficulties you will face, (so) my recommendation is to have a trial of three months. A2

There are some very difficult (patients) who are wide awake and alert on the ventilator but have no lung function left on their own...very often you try and not put them on a ventilator in the first place...you've got no other treatment except a new pair of lungs and so we do sometimes put patients on a ventilator for days, weeks, months and then allow them to die...The decision is helped by having clinical evidence and weighing it up beforehand. D6

A baby could be born at 400 grams which elsewhere would not be allowed to live. When it comes out it's alive, kicking and breathing. Am I just going to let him die, of course not, that child comes down here and gets the full treatment to start with. This buys time. A12

Clinical experience was regularly cited as one of the most important factors and the indication was that 'experience' was as important as any concrete evidence:

The decision is made on an individual basis using experience, maybe second opinions, parental wishes, the baby's condition, the nurses' experience. A7

My young team wanted to drain his kidneys and then review his management and I was outvoted there. All the other consultants agreed with me and the man died a week after starting terminal care. My junior staff were very concerned by this...We are going to meet more of this...they haven't got access to people with great experience. A26

Today I made decisions on three people with head injuries that they won't be treated. My criteria is experience - there are no hard and fast rules. Some people will pull out all the stops because they are unwilling to make moral decisions about not treating. It's easier to treat all and uphold the sanctity of life. B7

Doctors tend not to publicise their failures, their mis-diagnoses. Until this becomes professionally acceptable,

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[191]Time-limited trials are also 'highly recommended' regarding artificial nutrition and hydration when the effectiveness of a procedure and what the benefit-burden balance will be: See: Smith DH, Veatch RM (Eds). *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying. A Report by the Hastings Center.* 1987 The Hastings Center, Indiana University Press, Bloomington and Indiapolis at p61. The question must be whether it is for the patient's benefit or for the doctor's psychological benefit and to provide protection against litigation.

the quality of evidence available for directing treatment decisions will remain poor.[192] An important point, was made by one consultant:

> *How many persons were treatable that I didn't treat I don't know...we tend to protect ourselves from the stress of knowing.* D13

Another problem, which no one mentioned, is that scientific knowledge is growing rapidly and future illnesses predictable. If it is possible to identify that a critically injured person will develop dementia in the near future. or carries a gene predisposing him or her towards violence, would this be included with the evidence on which to base treatment decisions?[193] To withhold treatment on such grounds seems immoral. Even if there was absolute certainty that the future illness/event would become actuality, society may prefer to respect the privacy of its members from unwarranted intrusion.[194] The growth in clinical evidence, whilst making some decisions easier, will create new dilemmas for the clinician and society.

3.4.1.2 Quality of Life

This was of great importance although QALYs were not used indicating that the QALY model is purely of academic interest and unworkable 'at the bedside'. The assessment of quality of life seemed to be a purely subjective assessment made by the clinician often with little patient input regarding what an acceptable quality of life would be or what his/her life goals were. Typical comments included:

> *QALYs aren't used as such. We obviously think about the quality of life of the patient before any treatment, we don't actually quantify that.* D6

> *If I think the patient is not going to tolerate it, their quality of life is not going to be enhanced...I tell them that's my opinion (not to have treatment) but they should have a go if they are in any doubt.* A2

> *Someone who is unlikely to have an independent existence out of hospital for less than six months I would not dialyse. I would not dialyse dementia and very elderly patients over 80 years who were unconscious at the time of referral.* A2

> *The most important thing is quality of life...If there is no prospect of recovery and complete change of personality, what quality of life are you enhancing by treating?* D13

> *Quality of life is probably the crucial one as far as children are concerned.* B8

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[192]A recent editorial indicated that the error rate in medicine is equivalent to at least 20 aircraft landings at Heathrow being potential disasters and called for 'greater willingness to discuss error openly at all levels of medical training rather than trying to hide from it'. Nicholson RH. Editorial *Bull.Med.Ethics* 1999;**146**:1.

[193]For a discussion of similar issues see: Hargrave S. Row over brain scan that spots 'killer' babies. *Sunday Times* 28 September 1997.

[194]Even where future risks can be minimised, the right of the individual to reject preventative healthcare such as vaccination is upheld in this country even though some medical professionals might consider this an irrational rejection of scientific evidence. For instance, Schoen suggests that routine circumcision of newborn males is being rejected despite the future benefits he alleges will acrue to the individual: Schoen EJ. Benefits of newborn circumcision: is Europe ignoring medical evidence? *Arch.Dis.Child.*1997;**77**:258-260. His argument is rejected by Rowena Hitchcock (Comment. *Arch.Dis.Child.*1997;**77**:p260) on the grounds that circumcision is an assault. The Human Rights Act 1998 may help to protect individuals against such interventions in the future even if scientific evidence becomes overwhelmingly in support of the procedure in question.

Some consultants took a paternalistic approach and alone would decide not to treat, often based on a dubious 'ethical' approach of considering whether the predicted quality of life would be what they would want for their relatives:[195]

> *I'm a bit old fashioned. I tend to take somewhat of a paternalistic view of this...I weigh up the judgement on quality of life in terms of the individual patient...and one decides not to start (treatment) if the quality of life is such that there's nothing to be gained. I am perhaps guilty of not discussing it in a wider sense with patients and colleagues. I'm a great believer in the quality of life.* B2

> *If it were my dad, my mum, my sister, my child...what treatment would I consider optimal.* B15

> *What would I want if I was her or she was my mother.* A29.

There was an indication that the options offered to the patient (or relatives who often were used as proxy decision-makers) would be tempered by these considerations. This approach is very questionable, legally and ethically. The doctor is not expected to act as patient surrogate since s/he usually knows too little about the patient to be able to speak for the patient. To withhold treatment on the basis that, if s/he were acting as a proxy decision-maker for his/her own mother or child, this is the decision s/he would make, is unacceptable. The patient is not the doctor's relative. If the patient is competent, s/he should be involved.[196] If incompetent, the decision must be in his/her best interests. The doctor is under an obligation to discover, as best possible, what constitutes the particular patient's best interests. This requires communication with others, not a transference of one's own family values and personal beliefs onto another.

3.4.1.3 Balance of burdens and benefits

Several doctors spoke of balancing burdens and benefits (in other words, invoking the principles of beneficence and non-maleficence. There seemed a consensus that, for the elderly patient, particularly one with dementia and/or multiple pathologies, treatment for the presenting problem would be unduly burdensome. Typical comments included:

> *We look at the pros and cons and if the risk of the procedure is high and outweighs the benefit, I advise them against.* B3

> *First and foremost, what is going to benefit the patient and what the trade-off is in terms of side effects, so I have no difficulty in not offering treatment to a patient where I think the side effects are likely to outweigh the benefits.* C5

> *When you can see that someone is pretty well going to die, or if by chance they survive and they're*

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[195] All the consultants who took this approach were male but that is probably irrelevant since the number of female consultants interviewed was very small because fewer women reach consultant status in this country.

[196] The doctrine of therapeutic privelege is sometimes invoked when it is felt a patient could not cope with the news about their condition. However, it may be that the difficulty is more the doctor's than patient's and some doctors are less able to guage the ability of the patient to cope, or some doctors are less comfortable with communicating bad news.

going to have a major problem or a weakness down one side or mental problems, usually we are very reluctant to push hard, just maintain life provision. D5

The decision has to be based on whether this is going to improve quality of life or is this going to make things worse, for instance, if the patient had a stroke whilst under anaesthetic. D11

Only one interviewee spoke specifically of applying the Beauchamp and Childress principles:

I use the principles because at least it proves you've thought about it by using this framework, which is almost certainly inadequate, but it's got international respectability. A6

One consultant orthopaedic surgeon with a large paediatric caseload spoke of the difficulties faced in balancing present benefits for cerebral palsy sufferers against future problems:

Treatment of cerebral palsy hip dislocations and...spinal curvature in cerebral palsy and spina bifida. The problem is...the neuromuscular abnormalities that are causing the deformity...are going to be there right through. If you get their hips right in middle childhood there is a tendency for them to hit other problems in teenage and adult life[197] *that may negate the value of what you are doing...The difficulty is that it's not easy to randomise a treatment that is very intrusive against nothing because the logic to the patient is, 'why do a very intrusive treatment if you are not sure it's going to be substantially better for them?'* C2

At times treatment may be given which would, with hindsight, have more appropriately been withheld. To balance benefits and burdens means assessing present and future quality of life. The lack of clinical certainty renders difficult this process. Heim and Steinbach question whether too little attention is focused on the quality of life and whether 'medical servitude is morally correct in prolonging the patient's hell'.[198] Particular difficulty occurs when the patient is a child.[199] Michalowski welcomes the fact that 'medical opinion of what is in the best interests of the child (is) not seen as determinative'.[200]

3.4.1.4 Patient wishes

Most consultants recognised the importance of patient autonomy and would not lightly ignore it:

One has to recognise individual choice and preference. D9

I have just seen someone this morning who has motor neurone disease...He is now in the situation where he is chairfast but he retains his intellect completely and we've already made one rational

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[197]Explained as due to the fact that they gain weight and the muscles don't keep pace with the bone growth.

[198]Heim M, Steinbach T. For whom the bells knell. *J.Med.Ethics* 1988;**14:**140-141 at p141. They describe a particular patient's situation. The reply, by Bryan Jennett (loc cit, pp142-3) reveals that inappropriate surgery is probably more common than realised.

[199]See, for instance, *Re T (Wardship: Medical Treatment)* [1997] 1 FLR 502. Was the mother of T correct in asserting that it was better for him to have a short life than one with major surgery and anti-rejection drugs for the rest of his life? This case will be discussed more fully in later but it is important to note that the court, unlike other cases where the parental refusal has been due to religious grounds, was prepared to hold that medical treatment to prolong life in a child whose current life was not 'intolerable' should not be given.

[200]Michalowski S. Is it in the best interests of a child to have a life-saving liver transplantation? *Re T (Wardship: Medical Treatment) Child.Fam.Law Q.*1997;**9,**2:179-189 at p181.

decision which says that if he loses his ability to swallow he will not be artificially fed. That's his decision. He has reasonably said, well I know you can do it but what benefit does it bring me?...He is prepared to entertain a tracheostomy because it will help him to cope with distressing symptoms whereas an intervention such as putting in a feeding line would be seen as a malicious intervention. D9

When you become physically or mentally very ill - how much is retrievable? (I ask:) can we give you back some control over your life? If we can it might be worth having treatment. D13

Sometimes, the consultant would seek to discover the goals and aspirations of the patient. 'Normality' was considered important.[201] One consultant psychiatrist described how his patients lacked what would appear to be 'normal' aspirations:

We put down unmet needs (on our care planning forms) but we found patients never put down work; they've given up all hope of getting it so they don't see it as an unmet need anymore even though they would actually like it. A4

Three (male) consultants indicated that women were manipulating the health service. Probably male patients can be just as manipulative and this may indicate prejudicial rejection of female assertiveness or communication barriers.[202] No one admitted practising 'protective medicine' yet the rising number of Caesarean sections suggests this and this could be interpreted as manipulating women.[203]

A lot of women are now asking for Caesarean section where there isn't a medical indication...they want it for convenience of timing so it is convenient for the husband to have time off work that particular day. A1

Some women just don't want to go through labour - it is just too much like hard work and I just say yes. A1

A lot (of hysterectomies) happen because a patient says their periods are awful. Realistically we have no way of saying no they're not. We then say OK, we're not going to withhold treatment.[204] B19

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[201]One consultant described how certain operations are tightly restricted by the purchasers and he is required to make a special case for certain 'cosmetic' procedures such as breast reduction. He gave me a copy of an article which he considered highlighted the social difficulties some patients face which have a major impact on their lives. Being able to lead a '*normal*' life was one of the most important considerations in his opinion. (B10)

[202]No consultant made any similar comments about male patients even though, with regard to screening for prostate cancer, the consultants interviewed indicated that there was little or no point and no doctor ever has it done because the surgery is worse than the need to pass urine during the night. So, scope for similarly disparaging remarks about men existed but none was made. Gilligan questions whether 'physicians' disregard for their patient's wishes' could be influenced by the fact that the patient and/or the relative was a women and suggests that 'courts consistently portrayed female patients as less capable of rational decision-making than male patients'. Gilligan C, Raffin TA. Whose Death Is It, Anyway? *Ann.Int.Med.* 1996;**125,**2:137-141 at p139.

[203]This has been a problem in America for several years. It is also an increasing problem in France and other European countries (*France-Soir* 25 Sept.1997 30% de cesariennes). Wendy Savage considers that 'CS is being used too freely by inexperienced, poorly supervised staff in the labour ward misinterpreting electronic foetal heart traces, who don't know how to deliver babies presenting by the breech' (*NHS Magazine* Summer 1997) The Audit Commission has reported that a caesarian section costs about £1,100 compared with £360 for a normal delivery. A particular issue is whether women should be forced to have Caesarean sections in the interests of the unborn child - this will be discussed later since there are several important court cases which have considered the problem. Audit Commission for Local Authorities and NHS in England and Wales. *Accounts for the 7 month period ended 31 October 1997. HC 668 1997-98.* 1997 The Stationery Office Ltd., London.

[204]Exactly the same tends to be said about women with learning disabilities when requests are made for sterilisation by hysterectomy.

Very few consultants would actively discuss issues such as whether a patient wanted to be resuscitated with him/her:

> *I think we could do more than we do. Where it could be done is before big elective operations that are vascular, abdominal surgery. Now they always have associated ischaemic heart disease and something could go wrong with them.* A31

> *I have anxieties about talking to patients about doctors willingness to resuscitate them or not, I feel it can upset the doctor-patient relationship.* A35

However, the guidelines from hospital B state that 'if at any time patients or their relatives request an attempt at resuscitation contrary to medical opinion, this should be carried out'. This is highly significant because it acknowledges patient autonomy and goes beyond the general principle that a doctor cannot be forced to provide treatment s/he thinks is inappropriate.[205] It also accords a 'right' to the patient's relatives not recognised in law to override the doctor's medical judgment. There is an inherent disagreement apparent over the general support for clinical evidence as being the prime factor in deciding what treatment to give or not and this willingness to accede to patient/relative wishes even where evidence suggests resuscitation would be futile.[206]

> *If I think it is against the patient's medical interest to be prescribed a treatment, for instance, keeping somebody alive that would in fact be prolonging their dying rather than actually improving their quality of life, I would still be very strongly guided by the patient and their family and would not wish to overrule that without having spent a lot of time discussing it with them.* B1

The consultants were not specifically asked about attitudes to euthanasia.[207] One geriatrician indicated his opposition to euthanasia or physician-assisted death:

> *I have to obey the law and I believe I should obey the law. So I will not do things that will rapidly cause patients' deaths even if they are suffering a lot because it's rare not to be able to get on top of physical suffering.* A22

Only three of the eighty-five consultants mentioned advance directives which seemed surprising given the topicality of the subject. It possibly indicated that clinicians actually come across them so rarely that they seem irrelevant to routine decision-making. If the patient's actual situation was unanticipated, or the directive not 'properly' drafted, they indicated it could be appropriate to ignore the advance directive. This raises huge ethical and legal questions regarding who interprets whether the circumstances match the directive

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[205]However, patient autonomy is not given as much weight in this country as it is, perhaps, in the States. Thus, Mello and Jenkinson believe that 'physicians retain a larger degree of decision-making authority and clinical freedom' so this 'has kept the use of CPR from becoming as routine as in the U.S.' Mello M, Jenkinson C. Comparison of Medical and Nursing Attitudes to Resuscitation and Patient Autonomy between a British and an American Teaching Hospital. *Soc.Sci.Med.* 1998; **44,**3:415-424 at p416.

[206]Mello and Jenkinson, supra at p419, found that senior doctors would be more likely to withhold CPR they felt was futile but junior doctors would attempt resuscitation. The doctors interviewed for this thesis were all of consultant status. Whether the difference is due to greater clinical experience influencing the decision, or greater personal belief in themselves and their power of making correct decisions is impossible to tell.

[207]One of the reasons patients may request euthanasia is because of inadequate pain control. See, for instance. Ruddick W. Do doctors undertreat pain? *Bioethics* 1997;**11,**3&4:246-255; Somerville MA. Pain and Suffering at the Interfaces of Medicine and Law. Univ.Toronto LJ 1986;286-317; Wilson WC et al.Ordering and Administration of Sedative and Analgesics during the Withholding and Withdrawal of Life Support from Critically Ill Patients.*JAMA* 1992;**267,**7:949-953and Vangen S et al. Ethnicity and use of Obstetrical Analgesia: do Pakistani women receive inadequate pain relief during labour? *Ethnicity and Health* 1996;**1**,2:161-7. Palliative care is still a new science. The University of Bristol was the first to set up an MSc in Palliative Medicine (October 1997).

sufficiently.[208] If the responsibility is the clinician's, patients need reassurance that protective medicine will not put their interests last.

> *I take into consideration any properly drawn up advanced directive.* A3

> *When the patient is not in a fit state to make their wishes clear it's difficult unless you know the patient's wishes from previous either written or oral statements.* A15

> *I accept the principle of a living will...but also recognise that the patient's attitude to life and death and expectation of life and quality of life does change with time and the passage of the illness. Often a view expressed three years before the terminal illness gets to grips is different from the opinion and the expectation of the time of the terminal illness. You can't anticipate which way the patient's going to change their mind or may wish to hang on as long as possible in the hope that something will be done to their advantage. Other patients' view that enough is enough. So giving patients a view on this is of paramount importance.* A35

> *The reason (some) doctors won't let patients die with dignity is firstly that they practice defensive medicine increasingly which is appalling...(and)...dealing with someone in their 30s and having to say that they have a fatal condition, there is an awful lot of baggage around them that makes them much more difficult and much more time-consuming and more challenging.* D9

Much emphasis has been placed on patient autonomy in recent years which can only flourish in a climate of trust between patient and doctor. If the doctor distrusts/resents the patient's motive for requesting treatment trust is lost. For patient wishes to count in guiding treatment decisions, the patient needs enough information to contribute as an equal partner in the process yet it seems rare for patients to be involved in discussions about whether they should be for resuscitation or not.[209]

3.4.1.5 Social circumstances

The circumstances of the patient was taken into account by many of those interviewed. Whether they had support at home, whether they were, or would be, a burden to others all seemed relevant to deciding whether to operate on a patient or not:

> *The history that the patient gives, the past history that they give of the problem, the social history, circumstances under which they live. Every single factor is important: inability to cut toe nails, nobody to help, inability to get up the stairs, nobody to help go to the toilet.* D4

> *An 18 year old boy with very severe cerebral palsy who could not be weaned from the ventilator.*

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[208]Several consultants separated situations created by illness or accident from those created by the doctor or surgeon. Hence, every operation under anaesthetic involves a form of resuscitation and a DNAR order, or Advance Directive saying, do not resuscitate, would be ignored. Similarly, if the patient suffered a heart attack as a result of a reaction to a drug given by the doctor. This contrasts with the finding of Mello and Jenkinson, op cit n205 at p419, who found all British doctors and nurses would always follow DNAR orders.

[209]The concept of informed consent and the extent to which English law requires consent to be fully informed will be examined in a later chapter. It will suffice to state here that consent need not be fully informed in order to have been validly given. The extrapolation from this will be that refusal of treatment need not be fully informed either but this is a possibly more contentious point.

Home ventilation would have involved huge cost but would not have extended life indefinitely. Principles guiding us were the quality of life for the patient who would be in distress and...the immense burden to the family. D1

It might have considerable implications for the whole family unit if their condition is treated. B9

It is a grave indictment of society and the inability of the welfare state to deliver what was promised if the lack of support at home is a reason to deny a patient an operation. Yet it seems accepted that treatment should be restricted due to social circumstances thus validating an 'aristocracy of the fortunate'.[210]

Even when the decision should be made in a child's best interests, the parental burden could be decisive:

One has to take into account the needs of the family and society but the primary issue should always be the best interest of the child. C14

This baby is only two kilos or so. But if the parents decide that the commitment that it means for them...that is what they want to do, then...we would go with what they want. A34

Short bowel disease is a good example.[211] I've had almost identical patients within months of each other where one child was a desperately wanted child of older parents who would not have another child and they were desperate for everything to be done. The other was a child of very young parents who could not face the prospect of going through all that is involved. In these cases the decision was fairly easy even thought the underlying situation was virtually identical as regards these two babies. C9

Several questions are raised by these examples. Do parents have a right to deny a child potentially life-saving surgery? If clinical evidence suggests surgery will merely prolong dying and add considerably to the discomfort of the child what justification is there for operating? Should society deny the opportunity of treatment on cost-benefit grounds? Are surgeons guilty of seeking to advance their knowledge at the expense of the voiceless? Should such decisions be taken out of the hands of parents and doctors and given to the courts since neither is always committed to placing the best interests of the child first?

Two consultants indicated that the burden on carers can lead to patient abuse and/or requests from the patient to stop treatment. They appreciated that the vulnerable should be protected:

A lot of old people would do what their relatives wanted. Because even if the relationship is bad, a lot of them feel the last thing they want is to end their lives with the relationship with their children broken. Even old people who are frankly physically abused by the younger people will usually not disclose this because they say my life's nearly over, I'm not going to muck up my kid's life...You need someone to stand up for them and not let them be walked over. A22

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[210]Harris J. Unprincipled QALYs: a response to Cubbon. *J. Med. Ethics* 1991;17:185-188 at p186.

[211]This is a condition found in some new born babies. It is inevitably incompatible with life. Transplantation has been attempted with limited success as in the well-known case of Laura Davies. According to the consultant, none has yet survived beyond early childhood and those that have undergone active treatment have spent most of their lives in hospital.

We had a patient who was saying she wanted to withdraw...but it became clear that she had wanted to stop because she felt she was a nuisance and a burden to everyone and you can understand that there can be pressure to stop treatment on a busy ward and having stopped treatment we reintroduced it. A2

Regarding infertility treatment, doctors have legal powers to reject patients. The welfare of the future child has to be considered but sometimes personal prejudices could lead to imposition of conditions which could be considered *ultra vires* if challenged. Robinson objects to such discrimination since 'objections...are based on prejudice not reason'.[212]

We use social circumstances as well. I think fertility is a different area than other conditions because of the implications of bringing a child into the world and looking after a child in the future so you are looking at suitability to be a parent...if we're going to spend resources on them then I think it's right to look at their suitability to be a parent. A25

The consultant who runs the fertility services here has...very strict views on that particular aspect. One of them being, if you're using donor sperm or eggs, the couple must be married because the rate of separation after using donor eggs or sperm is greater because there is always some resentment that the child is not really theirs. So on that basis he insists the couple is married and therefore by implication we don't treat gay couples here because they can't be married legally. A25

3.4.1.6 Resource implications

Allocation of resources within society has been considered earlier[213] so the effects of resources on individual decisions will now be made as a reflection of the principle of justice. Most consultants considered it proper to allocate limited resources as wisely as possible though a few refused to consider finances:

Cost should not be the sole criterion but it may have to influence the decision as there are limited resources in the country and it is not fair to gamble very large sums of money when there is very limited chance of success. D1

A lot of the decisions we make about the use of our resources...are to a certain extent driven by financial considerations as well as the patient's best interests. C6

You have to temper clinical decision-making with resources. A20

We don't make decisions on individual patients because of resources but... (healthcare) is rationed because of the time it takes to see us. D7

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[212]Robinson BES. Birds do it. Bees do it. So why not single women and lesbians? *Bioethics* 1997;**11**,3&4:217-227 at p220. The Warnock Committee did not go so far as to insist that couples receiving infertility treatment should be married (Report of the Committee of Inquiry into Human Fertilisation and Embryology (Cmnd 9314) 1984 HMSO, London at para 2.5). The Glover Report felt there were 'strong grounds for unease about reproductive help where the family circumstances may impose a serious handicap on the child' *(Fertility and the Family. The Glover Report on Reproductive Technologies to the European Commission,* 1989 Fourth Estate, London) but felt the interests of society were better served by not restricting the concept of 'family'. The English legislation requires that the 'need of the child for a father' is one of the factors to be taken into account: Human Fertilisation and Embryology Act 1990 s11(5).

[213]See discussion in Chapter Two.

I never use resources as a criterion. A14

Constraints on clinic time (what one consultant termed 'timing costs'), once the patient has actually reached the top of the waiting list and has been seen by the consultant, could dictate what treatment was offered with little attention seemingly paid to patient preference or clinical effectiveness:[214]

When you do a hysterectomy, you may have to consider removing a woman's ovaries, and this has an hormonal impact. One way round is to put in a hormonal implant at the time of the hysterectomy but I don't do that. I put them on tablets or patches of oestrogen. The tablets are cheaper and that way I don't have them come back to my outpatients on a six monthly basis to have the implant changed. So the considerations are partly not clogging up my outpatient clinics and partly it's a decision to use a cheaper method. A1

We're overspent so we are looking at ways of rationalising the use of tests. D3

Several consultants were concerned at the risk of being held professionally liable for providing inferior treatment. Typical comments included:

You do a second best op and take higher risks because of the lack of resources. B7

I've had conversations with GP's about growth hormones. They can't afford it, their budget is..., if they give this child the hormone they may not be able to give the next coronary bypass. C12

We're often offering a sub-optimal therapy. A4

The way treatment interventions were presented to patients could influence whether the patient opted for treatment or palliation:[215]

We never say you could have a big expensive operation but we are short of cash this week...What we do say is there is a big expensive operation that may suit you but you are 85 and you do live in a nursing home and the chances of your survival are 50:50 and no one loves you and you want to die so maybe we shouldn't be quite so enthusiastic about doing this sort of routine. D8[216]

The burden on healthcare staff, particularly in adult and neonatal ITU, was also mentioned at times because this could lead to staff shortages and restricted resources although few openly admitted to considering the burden on themselves:

My role is to produce the best possible outcome for each patient and my personal opinion should not

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[214]One consultant interviewed described how the knowledge that there are no more available 'slots' for haemodialysis influences decisions whether to recommend CAPD instead. At least he is aware that his decision-making (or the choice that he offers to the patient) is being influenced by what many would consider inappropriate criteria.

[215]Lindgren J. Death by Default. *Law and Contemporary Problems* 1993,**56,**3:185-259. Lindgren points out (at p207) that 'the responses people give are highly dependent on how questions are asked'. This statement is also applicable to the questionning of the consultants for this thesis.

[216]In fact, although this consultant did not qualify his comments, others indicated that they would similarly present active treatment eg. surgery, in a way that reduced the likelihood of the patient wanting to proceed but that they would use tact in how they represented the patient's own situation to them. It is probable that this consultant also would not be so brutal face to face with the patient.

come into the matter. D10[217]

I've been here (intensive care) for fifteen years and that's a long time. A lot of the staff get, well burn out isn't the right term, but a lot of the staff, particularly nursing staff leave ITU after that time. A31

Patient wishes sometimes conflicted with treatment rationing but it was felt justifiable to spend limited resources on satisfying them if society has not been specific about how it wants its money spent:

In obstetrics...women are being offered choices...In terms of resources, it involves huge expenditure, a Caesarean section costs much more than a vaginal delivery and we are going to have to address that eventually.[218]*..I'll keep doing it...until the public purse says that this particular procedure, in line with other procedures like tattoo removal, that are not clinically indicated, will not be available on the NHS.* A1

Public ignorance is not a reason to allow these practices to continue. This promotion of patient autonomy over justice for other users of the healthcare service is out of step with the increasing acceptance that clinical need should be the starting point for decision-making.

3.4.1.7 The patient's age

There were differences of opinion expressed as to whether age alone, apart from clinical effectiveness, should play a part in the decision-making process. Unless some scarce resource like donor organs or great expense was involved it seemed inappropriate as a single criterion. Those predominantly involved in treating elderly patients were vociferous in their defence of the rights of these patients to equal access to healthcare possibly due to self-protection:

My gut feeling is that age per se should not come into it...If you actually ask...(the elderly)...the same question...they might say, give the chance to the younger patients. D13

We seem to start up with the assumption that it won't benefit the older ones whereas it should be the other way around. You're innocent until proven guilty. D13

Others accepted the 'fair innings' approach. It seemed evident that patients' opinions could be influenced by social debate so as to be more altruistic:

The old tend to be fairly rational about the fact that the young are treated first. A34

I think the fair innings idea does have merit. I think it's probably somewhere around the mid 70's. It does seem to be the age that people can readily live to and provided they are not having chronic

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[217]This consultant described how he would sometimes have a patient admitted to ITU, who would probably eventually do just as well without specialist care after surgery but whose recovery rate would be hastened, simply because it was good for the morale of the staff to have a patient to look after who would recover and be appreciative of their work particularly if they had had a bad run with lots of patients dying.
[218]He indicated that hospital A performed 50-100 caesarian sections a year without clinical indications and this number is rising. He also reported a study had indicated that 60% of female obstetricians would opt for caesarian sections themselves.

illnesses they're really not bad. Beyond then people really do start to develop an awful lot of chronic illnesses that limit their mobility and all the rest of it. Certainly from the elderly patients I've talked to...that's the sort of time that they begin to feel that they have had their innings. A5

There is an age limit of 70 years beyond which it is unusual to consider transplantation. A30

The surgeons tell us they won't transplant anyone over 70...I leave them on the list if they are still waiting but a few patients will take themselves off the waiting list when they get to 70 saying 'I'm 70 now and it's not fair that I'm on'. A2

Surprisingly, extreme youth seemed to represent an opportunity to withhold treatment in a way that would be impossible once the child was older:

It is the young babies...one knows the effect it has on family lifestyle together with how difficult it can be for some of these babies. They are probably the only ones in whom, in paediatrics, we seriously consider not treating. Most other children we would treat. So they're ones in a way, where the outcome is sufficiently debatable, that one could think that you could justifiably consider an option of not treating. (Interviewer: So, for the older ones, the sanctity of life principle comes into play?) Yes. A34

This provides a worrying insight into how 'personhood', and possibly any proven ability of the carers to cope, can tip the balance from non-treatment to treatment. The very young child is as vulnerable as the very old or demented and rarely are decisions to deny treatment reviewed by independent arbitrators.

3.4.2 The parties involved in the decision

These included:

a) the patient

b) the relatives

c) the healthcare team

d) the consultant

3.4.2.1 The patient

Most of the consultants asserted that competent patients should make their own decisions based on information provided by the doctor however, qualifications often crept in and their commitedness to patient autonomy seems less than initially stated when comparison is made with earlier discussions, particularly regarding advance directives.[219] Typical comments included:

If the patient is competent it is up to them. A1

If the patient is with it, it is up to them. D7

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[219]See: para 6.5.1.4.

If the patient is (competent) they have an input into the decision-making process but the decision is actually a team decision. B1

It's a joint decision between the doctor and the patient. B15.

Little mention was made of how much information the doctor should impart and an atypical comment was:

The final clinical decision should be made after full informed consent from the patient. D10

No one mentioned how they actually assessed competence. Regarding children there was less agreement about the extent of their involvement.[220] The Gillick test seemed applied in an ad hoc fashion, with age/physical development possibly being more persuasive than understanding. This might indicate defensive practice since understanding is harder to prove evidentially if challenged than concrete facts or maybe doctors prefer scientific evidence.

I'd say any child who is an adolescent or more has sufficient insight to contribute and would have a major say in what they feel. C13

Even quite young children can be involved. (but) .parents can feel guilty and push for treatments that are just not sensible. A36

Children can have a very valid and appropriate say in what they do or don't want to be put through. But for preschool children that input is very limited because of their intellectual inability to think ahead. For infants clearly even that communication is impossible, so in those situations the parents are a key part of the decision making process. C14

3.4.2.2 The relatives

Parents have legal rights to make treatment decisions for minor children but may be too partial or subjective. Sometimes, parental demands for treatment were felt to place too high a burden on the child. Several consultants spoke of 'Child B' in this context and felt they should not 'debase their role in medical leadership and their advocacy of their patient's interests by passive acquiescence to parental demands'.[221] One consultant with particular interest in ethics expressed this well:

There are two aspects that influence people's attitudes as to why the patient shouldn't be treated. One is a subjective approach where they feel that even if the child survived, they would be so severely disfigured and deformed they would have a terrible sort of life and it would be far kinder, far more humane not to save the child. They're putting themselves into, what they imagine is, the mind set of a severely deformed crippled person and imagining that it would be terrible because they see the big picture and wouldn't want that for themselves. The other is a more objective approach where

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[220]Not all the consultants treated children.

[221]Campbell AGM et al. Treatment dilemmas in Neonatal Care: Who Should Survive and Who Should Decide? *Annals of the New York Academy of Science* 1988;**530**:92-103 at p97.

professionals feel that looking through the results from our past experience somebody with this type of injury does not survive. It's a tremendous undertaking to attempt treatment and perhaps on balance it's best in this resource-limited environment that the child would be better not treated. B9[222]

Regarding other incompetent patients the general approach favoured involving the relatives. Typical comments included:

If they (the patient) are not competent, then the relatives. A1

If the patient is not with it, then their closest relatives should be involved. D7

Some consultants would talk with relatives but considered the decision their responsibility not the relatives. Gilligan supports this approach: '(i)f the patient's loved ones must make life-and-death decisions on the patient's behalf, they will probably have feelings of grief, guilt and confusion'.[223]

If they (the unconscious elderly patient) are not going to live very long...I would discuss it with the relatives and tell them what I think is the right thing to do because I don't think relatives should be asked to make these decisions - that is quite wrong - they have come for an opinion and I give them an opinion but give them the option to disagree with me. A2

Relatives wishes in law have no force. But in fact we do actually go and talk to them quite a lot. Largely not because we want to give decisions over to the families because I think that's wrong, I think that's an abdication of my responsibility...but I do want to listen and I also want to not do things that upset or hurt them if I possibly can. A22

Others took a team approach with family input:

If the person is not capable of making their own decision, the same principles apply (a team decision) but the family take a much more prominent role but the patient is still important because, although they may not be able make a verbal contribution, sometimes people can communicate all sorts of things non verbally. You may or may not pick that up. C1

When...there is no hope you have a discussion with the family and friends by which time you will have ascertained their advocacy status whether they were close, whether they were remote, whether they have vested interests, all these factors are real, and you will have a fairly pragmatic discussion and if the people you are dealing with appear legitimate in their concerns, and you can do no more than get a feel for their legitimacy, and they agree that on their knowledge of the person concerned that they would not want their life sustained at any cost, then you can make very reasonable decisions.

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[222]This consultant described how he had recently been involved with a three year old child who had suffered extensive (90%) burns in a house fire. At the same time, the hospital was treating a child of similar age who had suffered a major head injury with massive brain damage. He spoke of the difficulties even experienced staff had coping with the idea of treating the burnt child and contrasted the fact that the brain-damaged child, who looked normal was, in fact, not the child it had been: it had lost everything that had made it that child, yet staff were in favour of continuing treatment, but the burnt child, under the burns, had no brain damage and was still the little boy he had been. Both children later died.

[223]Gilligan, Raffin TA. Whose Death Is It, Anyway? *Ann.Int.Med.* 1996;**125**,2:137-141 at p138.

Often, the feeling expressed was that relatives, less than patients even, did not have the requisite level of understanding to be able to contribute to the decision-making process and for that reason should be excluded. This view, possibly evidential of feelings of professional superiority, was challenged by a minority who recognised that improved communication skills and less stereotyping could enhance relatives and patients understanding:

> *(If you) go into in depth knowledge most of it tends to go over their heads - they don't have what's actually required for a deeper understanding. If somebody is very qualified and very intelligent then fair enough if they're able to take it, but generally speaking I hope the relatives should have enough trust in the doctors to be acting on their behalf, but that trust has to be earned...With the political scenario and the media as it is, that trust has been dented.* D13

> *Our role is not to denigrate them because of their limited understanding but to try and make sure we provide them with the appropriate understanding in terms they can understand and can accept so that they can be involved in that decision making process.* C14[224]

Families often expect to be involved even if the patient is competent. Sometimes patients want this but assumptions in favour of family involvement can lead to difficulties which some prevented by only including relatives with the patient's agreement.

> *I don't think it's anything to do with the relatives...it's a contract between the consultant and the patient.* A24

> *I would rather leave it to the patients who they wanted involved.* C1

> *It is difficult when you have someone on the ward who really does not want their relatives to be involved but the relatives want to be involved, if you say, well, I'm not discussing it with you, it's always very difficult.* A4

Relatives may disagree over what is best. Kipnis and Gerhard note that the principle of non-maleficence is 'most likely to be violated when relatives and other decision-makers are given too free a hand in medical decision-making'.[225]

> *I was looking after a patient for a colleague over the weekend and I was told that care was being withdrawn on the Friday and this was all sorted out and it became clear on the Saturday that the sons were extremely unhappy by the father's decision and it hadn't been sorted out and we reintroduced dialysis.* A2.[226]

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[224]This was a very senior consultant with many years experience.
[225]Kipnis K, Gerhard A. Some Ethical Principles for Adult Critical Care. *Hawaii Med.J.* 1995;54:482-5 at p484.
[226]An analysis of reported conflict situations will be made later where it will be possible to make a legal analysis as well as an ethical analysis.

Nevertheless, some consultants would use relatives in order to support their paternalistic opinion of patient best interests. In the first of two contrasting comments, the consultant admits to using duress to weaken the patient's decision not to have treatment although, if consent is not freely given, the doctor may lack a legal 'flakjacket'.[227] The second recognises that patient consent may be given under duress and tried to protect patients:

> *There are situations where the consent is withheld by a patient who is competent and we then talk to the relatives to apply pressure to comply with our advice.* A1

> *I think too much power is given to relatives...I think relatives can exert a lot of influence and emotional blackmail is often used and I think women may feel they should have treatment for their partner or their children rather than for themselves.* C10

Sometimes relatives would ask that the patient is not told the truth about their diagnosis as it is recognised that patients and/or relatives may 'give up before the situation is truly hopeless' because of their lack of medical knowledge.[228] Those consultants who raised this issue would not collude in deception:

> *The only times we have a little bit of trouble is when the relatives will come and say don't treat somebody, don't tell them they've got cancer. We can't not do that, it's total patient involvement. If one has to tell someone they're terminally ill, I will not tell the relatives first. I will talk to the relatives with the patient but we'll sit around together. But a lot of people do treat the elderly like children. Don't tell them they can't cope with it. It's wrong. They can cope with it if they're told in the right way.* D2

> *If somebody came into me and said well I really don't want my father treated yet I felt that the patient could have a decent quality of life after the treatment I would ask the patient what he wanted. I think it's the patient's decision with information from us.* D2.

It is clear that there is no real consensus even at consultant level as to what the proper role of relatives in decision-making is. Patient and family opinions regarding this could conflict sharply with medical opinions. Some doctors were not above manipulating relatives in order to promote what they obviously considered superior views to the competent patient's own. This derogation is probably more responsible for the erosion of trust than the media or politicians.

3.4.2.3 The healthcare team

Many of the consultants felt the decision should involve the healthcare team.[229] Occasionally, this approach excluded the patient and/or family extending the concept of therapeutic privilege which holds that if the doctor considers the patient will be harmed by the revelation of their diagnosis and involvement in their care, the

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[227] *Re W (a minor) (medical treatment)* [1993] Fam 64. A doctor who treats under such circumstances may be held liable for battery or held to have acted negligently by failing to act as a responsible doctor in his or her position would have done (the *Bolam* test). Legal issues are discussed in a later chapter.

[228] Bayles M, High DM (Eds) *Medical Treatment of the Dying: Moral Issues*. 1978 GK Hall & Co., Shenkman Publishers, Cambridge, Massachusetts at p81.

[229] This could be construed quite extensively to include not only junior and senior doctors, nurses but also occupational therapists and others.

doctor can lawfully exclude the patient.

> *We tend to involve the family as part of the team...nurses and doctors have to meet up and talk regularly and that way you don't get a funny decision being made at 2am which is contrary to what everyone else wanted.* B18.

> *I think it (dialysis) is a team issue. I always discuss it with nurses because it is interesting how different healthcare people have different attitudes - if you are the person turning the patient every two hours and seeing them moaning and groaning then you probably have a lower threshold for wanting to pull out than if you breeze in a couple of times a week.* A2

Much emphasis exists, currently, upon taking a multi-disciplinary approach to the non-treatment debate. However, these comments need to be considered cautiously in light of some of the following comments made in favour of the prime decision-maker being the consultant.[230]

3.4.2.4 The consultant

A minority of consultants considered the decision was theirs alone but many indicated that the final responsibility of taking the decision was theirs.[231] This seems starkly in contrast with public and professional opinion. Whilst legally, the consultant may be held accountable for errors and omissions made by his team, it is hard to tell whether this was a reflection of what they considered to be a caring attitude towards their team, or whether they believed the power to make these decisions was earned by them and belonged solely to them. If the latter, this would indicate, as some of the earlier comments show, that paternalism is still present within the medical profession. Typical comments included:

> *As a consultant one takes the final responsibility, that's what we're there for.* D2

> *A consultant has a duty to advise as accurately as possible using his knowledge and depending on the strength of his conviction he alters the strength of his argument.* C3

> *I feel very strongly that the most important person to be considered is someone who has expertise or knowledge of the particular disease and also the treatment options that are available. I think it's very difficult, if not impossible, for others to make a primary decision as to what treatment is given.* B2

> *The professionals should be leading the relatives...in a structured logical argument of the pros and cons of treatment, rather than expecting them to make the decision.* A36

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[230]Wilson Barnett likewise noted that 'Doctors usually say they value the nurses' opinion and need their input' but, citing Busby's study, during ward rounds 'the researcher witnessed a traditional picture where the doctor dominated the conversation, rarely asking for the patient's or the nurse's views...directing his conversation between the medical staff'. Wilson Barnett J. Inequality among health care professionals: ethical dimensions of their relationships. In Grubb A (Ed) *Challenges in Medical Care* 1992 John Wiley & Sons, Chichester pp155-169 at p158, citing Busby A, *The Nurse's Role in the Medical Ward Round. BSc Research Dissertation* 1990 Nursing Studies. King's College Hospital, London.

[231]In contrast, McLean found that decisions to withhold or withdraw treatment were made by doctors who 'always involved other medical staff and the patient's family as well as nursing staff' (at p172). It is submitted that her conclusion lacks authority due to the poor response to her questionnaire survey (only 4%), the methodology (giving questionnaires to delegates at an international conference) and the fact that if treatment was withheld or withdrawn this would lead to the patient's death and doctors are more likely to be cautious in how they approach such decisions. Her explanation that a possible reason for the poor response rate was because 'there is a lack of interest amongst those charged with making these important life or death decision' (at p180) seems inconsisted with the fact that attendance at a conference dealing with such issues suggests there is an interest. McLean SAM. Report: Withholding and Withdrawing Life-Prolonging Treatment. *Med.Law International* 1998;**3**:169-182.

An overall impression was gained that, the more experienced the consultant, the less likely they were to consider the decision-making process a matter of a 'whole team' vote. The opinions of the team were a valuable resource as were the views of the patient (or relatives) but, ultimately, the consultant should take the decision as to what treatment to provide. Some authors consider that the responsibility of the doctor has 'taken a back seat to patient autonomy in contemporary bioethics'[232] but 'team voting' can distort the decision-making process just as much as if the decision were made in an autocratic fashion by the consultant.

3.5 Discussion

Several factors, falling into broad, overlapping themes, are considered when deciding to withhold treatment. Before any other factors, consultants seem to consider the clinical picture (diagnosis, prognosis, disease management options) which could also encompass patient age/quality of life. The quality of life (which could encompass the patient's age/social circumstances) was important. The ability of the patient to express his/her wishes, the balance of benefits and burdens associated with treatment and resource implications were also relevant.[233] The social circumstances of the patient and burden on carers are also part of the burden to be evaluated so patients who are better situated and supported are more likely to receive treatment. This is a clear case of 'to those who have shall be given' since the principle of non-maleficence confers no obligation to positively benefit another.[234] Some consultants believed it fair to use age as a tool for the allocation of resources whereas others believed it was not the doctor's role to consider whether resources could be better used by another patient.

It can be deduced that apparently objective decision-making is actually very subjective. This is possibly why effectiveness of treatment was accorded such importance since it appears more objective than many of other factors and consequently 'trumps' other considerations such as patient autonomy, beneficence etc. Externally-imposed resource restrictions are also more objective although the injustice these produced was more readily recognised. However, this could owe more to how these restrictions interfered with the clinician's 'right' to recommend the most effective treatment. Patients rejecting treatment were also seen as interfering with this 'right' by some consultants who indicated their preparedness to question competence or use duress.[235] Gillon believes that 'the withholding of life-prolonging medical treatment when the competent patient refuses it is not only morally permissible but morally required'.[236] Thus, any doctor exerting duress, either personally or through others, must be acting immorally. Just as the doctor is under no obligation to provide treatment demanded by the patient if s/he disagrees with it,[237] the patient is under no obligation to accept treatment

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[232]Paris JJ et al. Beyond autonomy: Physicians' refusal to use life-prolonging extracorporeal membrane oxygenation. *NEJM* 1993;**329**,5:354-7 at p356. See also: Tomlinson T, Brody H. Futility and the ethics of resuscitation. *JAMA* 1990;**264**:1276-80.

[233]Lindgren, op cit n217 at pp228-9, lists the conditions which people surveyed in national polls consider are ones for which no treatment should be given. Many fall into the 'clinical prognosis/futility of treatment' category. Others relate to social circumstances such as dependency on family, living in a nursing home (regardless of mental state). The rest fall into quality of life categories which may include social circumstances. There seems to be agreement with the findings of this thesis except none of Lindgren's categories included availability of resources.

[234]Beauchamp TL, Childress JF. *Principles of Biomedical Ethics* 4th Edn 1994 Oxford University Press, Oxford at p190.

[235]Pijnenborg L et al. Withdrawal or Withholding of Treatment at the End of Life. *Arch.Int.Med.* 1995;**155**:286-292. They found (at p291) that the reasons given for non-treatment varied according to whether the patient was involved or not. In 59% of the cases observed, the patient was not involved 'mostly because of incompetence' (in over half of those cases the relatives were involved) and the decision was usually based on anticipated effectiveness of treatment. Pijnenborg et al conclude (at p292) that 'The considerations are seldom purely medical. Most often a physician has to weigh medical and non-medical burdens and benefits'.

[236]Gillon R. Euthanasia, withholding life-prolonging treatment, and moral differences between killing and letting die. *J.Med.Ethics* 1988;**14**:115-7 at p116

[237]See, for instance: Luce JM. Physicians do not have a responsibility to provide futile or unreasonable care if a patient or family insists. *Crit.Care Med.* 1995;**23**,4:760-766.

offered by the doctor.

The most concerning issue was that many consultants considered an appropriate decision-making model was to decide what they would want for themselves, or their relative and apply that to the patient before them - a form of substituted judgment.[238] The treatments doctors select for themselves and those they recommend in standard textbooks vary considerably.[239] As Wall has pointed out, if a deontological approach is taken to healthcare decision making, this suggests 'doing as you would be done by' but, if a teleological approach is adopted, the decision-maker can only discover whether the right decision has been made once the consequences of the action or inaction have been established.[240] Different people have different values. Projecting one's own values and beliefs onto another is unethical, more so when one is in a position of control over the other.

There was no overall consensus as to whom to involve in the decision-making process. No one approach or consultant seemed obviously better at reaching the 'right' decision than another. Academic enquiry has mostly moved to developing 'a model that designates who should choose'.[241] Lindgren suggests, 'individuals prefer family involvement in the decision to withhold treatment'.[242] He might cite the evidence of polls to support his conclusion, but this would constitute a grievous breach of trust for the individual who does not want family involvement; who prefers to trust the doctor to deal with him/her faithfully without having to voice family disunity. Ethical healthcare needs to have an individual face. Not only should the most appropriate treatment plan for the individual patient be sought but also the appropriate means of determining this plan. This means communicating with the patient and the healthcare team. Revealing information to the adult patient's relatives without prior consent breaches confidentiality. To then rely upon their input to the exclusion of the patient's violates the rule of fidelity.[243] This rule seems violated also when treatment is withheld because the health authority or other healthcare purchaser will not fund it yet the patient is not given this information.

A surprising number of consultants believed the decision was for doctors only. Whilst objective reasons such as legal responsibility and greater experience were cited, it seemed clear that several deemed this one of the powers, like those of deciding patient competence and therapeutic privilege which demonstrated their hierarchy within the organisation. Withholding medical treatment was considered proper practice by all the consultants. It was never undertaken lightly and a strong preference for having the support both of clinical evidence and the family was evidenced. Both provide doctors with 'flakjackets' against litigation. A principled approach was rarely taken consciously. Whether this indicates that doctors are more comfortable with concrete facts than esoteric considerations is impossible to conclude. Facts are easier to demonstrate in a court of law than what is 'reasonable'. Sometimes treatment would be initiated which it would have been better to withhold. Reasons given were that there was insufficient clinical data available to adequately support the decision to withhold or

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[238]This is in accordance with the BMA's 1998 consultation document *Withdrawing and Withholding Treatment* op cit n133, at para 2.9.2 where it suggests that one way for the clinician to decide what benefits a treatment holds is 'for an assessment to be made by the clinician placing themselves in the patient's position'. The use of 'substituted judgment' as opposed to 'best interests' will be discussed later in this thesis. It will suffice to note that the English courts have rejected the concept of 'substituted judgment' in favour of a determination of the patient's 'best interests'.

[239]Mackillop WJ et al. Non-small cell lung cancer: how oncologists want to be treated. *Int.J.Radiat.Oncol.Biol.Phys.*, 1987;**13**:929-934. Reported in Kearsley JH: Compromising Between Quantity and Quality of Life. In: Stoll BA; *Ethical Dilemmas in Cancer Care* op cit n124 at p44. They report that only 9% of oncologists making decisions about their own treatment (in a hypothetical scenario) would opt for chemotherapy as well as surgery because of the side-effects of chemotherapy. Similarly, one of the consultants interviewed stated that doctors with prostate cancer will never have surgery because they know that the prognosis is not particularly improved but the quality of life is usually impaired by resultant incontinence and impotence. Yet 'ordinary' patients are encouraged to have surgery.

[240]Wall A. Best Behaviour. *Health Service Journal Health Management Guide* No5 May 1995 pp3-5.

[241]Lindgren op cit n217, at p225.

[242]Ibid.

[243]Beauchamp TL, Childress JF. *Principles of Biomedical Ethics* 3rd Edn 1989 Oxford University Press, Oxford, at p39.

that there had been too little time for the patient and/or the family to come to terms with the diagnosis.[244]

3.6 Conclusion

The major difficulty is that, often, insufficient information is available to guide the decision-making process.[245] This lack relates to clinical diagnosis and prognosis and also the particular characteristics of the individual patient. Decision are based on imperfect knowledge with subjective, value-laden judgments filling the gaps. At times, quality of life seemed treated as if it were a concrete fact like blood test results. Reasons to withhold requested treatment were given, such as unlikelihood of conferring benefit, likelihood of causing more harm than good, or the fact that the intervention requested, though not harmful, represented a waste of scarce resources.[246] All these approaches, and more, were reflected in the responses to the interview questions.

The starting point for decision-making seems to be an assessment of available clinical evidence. Patient autonomy seemed important and some consultants indicated that they placed it above everything bar clinical evidence. However, patients can only exercise full autonomy when provided with accurate information. It was evident that competent patients were sometimes denied the opportunity to participate fully in the decision to withhold treatment. Some consultants tailored what they told patients in order to optimise the probability of compliance and some would use psychological duress. Refusals of treatment for religious or other 'irrational' reasons could lead to a querying of patient competence although most consultants who described such incidents said they were prepared to accept them unless the patient was a child. Treatment requests could be refused if clinically inappropriate or contrary to the doctor's beliefs although an obligation to refer the patient to another consultant may exist. Doctors know their peers and the courts will provide support when they exercise medical autonomy and refuse to provide treatment they consider inappropriate or wrong, yet they may fail to respect patient autonomy when competent patients refuse proffered treatment. Decision-making will be improved by greater acceptance of patients' rights to act autonomously. In order to do this, patients need to be treated as equal partners and informed about treatment options. Decisions on behalf of the incompetent patient are made 'in the patient's best interests' but, it is clear, from the literature and from the consultants that there is disagreement over what constitutes 'best interests'. No one expressed any difficulty in holding that death could be in a patient's best interests. It was interesting to note that one consultant could accept both treating and not treating two, virtually identical babies. In that case, and in others where the decision was based, to some extent, on the burden on carers, the decision seems to be made not in the patient's best interests but in the best interests of the parents/carers. In order to improve medical decision-making, it will be necessary to consider to what extent family and societal interests are, or should be, persuasive.[247] It is seems more appropriate that the patient's 'social circumstances and family urgings one way or another should be lesser considerations' than the patient's own decision for or against treatment.[248] Several consultants expressed concern over regional

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[244]See, for instance: Balfour-Lynn IM, Tasker RC. Futility and death in paediatric medical intensive care. *J.Med.Ethics* 1996;**22:**279-281.
[245]See, for instance the discussion of futility in Luce, op cit n238, and the debate over whether giving 'Child B' another bone marrow transplant constituted futile treatment: Entwistle V et al. Media coverage of the Child B case. *BMJ* 1996;**312:**1587-1591. Entwistle reveals that opinions ranged from a 20% chance of survival being considered futile to less than 2% chance being construed as futile.
[246]Luce, op cit n238, at p764. See also: Brett AS, McCullough LB. Defining the limits of the physician's obligation. *NEJM* 1986:**315:**1347-1351.
[247]Long TA. Infanticide for handicapped infants: sometimes it's a metaphysical dispute. *J.Med.Ethics* 1988;**14:**79-81 at p80. He is commmenting on the Kuhse-Singer attack on Ramsey but reaches no conclusion as to the merits of either position. See also: Kuhse H, Singer P. *Should the baby live: the problem of handicapped infants.* 1985 Oxford University Press, Oxford and Ramsey P. *Ethics at the edges of life.* 1978 Yale Univ. Press, New Haven.
[248]Rosin AJ, Sonnenblick M. Autonomy and paternalism in geriatric medicine: The Jewish ethical approach to issues of feeding terminally ill patients, and to cardiopulmonary resuscitation. *J.Med.Ethics* 1998;**24:**44-8, at p47.

variations and providing a 'sub-optimal' service. However, few were prepared to be open with patients regarding the effect service constraints had upon treatment options. Any proposals to improve medical decision-making must address this issue. Any recommendations must help address the injustice inherent in the consideration of social circumstances, age and support of patient.

CHAPTER FOUR

WITHDRAWING MEDICAL TREATMENT

Most decisions to withhold treatment are based on clinical opinion that it will neither cure nor prevent deterioration. Once started, it can be difficult to ascertain that treatment is not achieving anything beneficial. Decisions to withdraw treatment are often made even though treatment is maintaining the status quo.[1] Sometimes treatment withdrawal is triggered by patient request[2]or his/her relatives'[3] but some doctors feel uncomfortable with such requests and may attempt to use the courts to override decisions.[4] Other withdrawal of treatment decisions may be made by physicians against the wishes of the patient or his/her family.[5] This chapter describes how medical treatment is withdrawn from patients. As with the withholding of treatment outcomes can vary. Analysis of how treatment withdrawal is carried out in general will be made using the categories of whether discontinuing treatment results in imminent and certain death or eventual death over a period of a few weeks or whether it results in reduced quality of life. Then the way the consultants said they made decisions in individual cases is considered.

4.1 Outcome of Certain Imminent Death

4.1.1 Babies

Treatment withdrawal often involves babies with extremely low birthweight or congenital abnormality.[6] Often a period of intensive care treatment is initiated to see how the neonate reacts and to provide time for the parent(s) to come to terms with events.[7] This matches the *individualized prognostic strategy* (start treating in all cases but review regularly for indications of certain death or severe brain damage) identified by Rhoden[8] and adopted by McHaffie and Fowlie[9]. Common humanity obviously demands that non-medical care is not withdrawn. The BMA suggests this is a 'right'[10] of the infant and that 'withdrawing treatment is not withdrawing love and care'.[11] However, the child has few other 'rights', certainly not to life. Decisions are made in his/her 'best interests'.[12] Whilst the BMA considers the 'initiation or the withholding of treatment'

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[1]Examples would include the provision of artificial nutrition for a patient in Persistent Vegetative State or Motor Neurone Disease, or the provision of ventilation for a baby with lung damage due to prematurity.

[2]This would constitute Weir's category of personal treatment abatement. Withdrawal of treatment at the request of a competent patient does not present a problem in law, since to continue treatment in such a case would be unlawful. Weir RF. *Abating Treatment with Critically Ill Patients: Ethical and Legal Limits to the Medical Prolongation of Life*. 1989 Oxford University Press, New York at pp39-40. See Chapter Six for a discussion of the legal issues.

[3]Weir, ibid, suggests that this can be of two sorts: imposed treatment abatement and cooperative treatment abatement depending on whether the family and the doctor agree that the decision to withdraw treatment is in the patient's best interests.

[4]Only some relatives will have decision-making powers eg. parents of minor children.

[5]Sometimes the decision is fought in the courts as in the case of Child B: *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.

[6]A European study is examining the attitudes of staff to withdrawing treatment from neonates according to McHaffie (the EURONIC study). McHaffie HE, Fowlie PW. *Life, Death and Decisions: a reflection on neonatal practice.* 1996 Hochland and Hochland, Cheshire at p19.

[7]McHaffie et al, ibid, at p17, report that one study found that Britain uses the last strategy, America the first, and Sweden the middle one. For the study itself see: Young EWD, Stevenson DF. Limiting treatment for extremely premature, low-birthweight infants (500-750g) *Am.J.Dis.Childhood*, 1990;**144:**549-552.

[8]Rhoden NK. In: Treating Baby Doe: the ethics of uncertainty. *Hastings Centre Report,* 1986;**16:**34-42.

[9]McHaffie & Fowlie, op cit n6 at p17.

[10]BMA. *Medical Ethics Today: Its practice and philosophy.* 1993 BMJ Publishing Group, London at p82.

[11]Ibid, at p83.

[12]See discussion later in this thesis regarding the interpretation of 'best interests' by the courts and the possible impact of the Human Rights Act 1998.

the doctor's responsibility, withdrawing treatment can no longer be seen as a matter of clinical prerogative. By the time the decision to withdraw treatment comes to be made, the parents will have more understanding of their child's condition and the way 'things work' in hospitals and will be better able to participate than if they had suddenly been presented with a seriously-ill newborn baby. It seems agreed that parents should be involved in decisions to withdraw treatment.[13]

Particularly difficult are cases where the baby is able to leave hospital only to return later with severe lung damage due to prematurity which is currently untreatable. Eventually, it becomes necessary to decide whether to withdraw further ventilator support or antibiotics. Some argue that such babies have been 'over-treated' and treatment should be withheld initially.[14] Stinson describes such an infant whose iatrogenic problems included retrolental fibroplasia, infections, broken bones, pulmonary artery hypertension and brain seizures, none of which would have occurred had he not been 'saved' by the use of the ventilator.[15] The tragedy is that the family will have built up a relationship with the child, who is old enough to have a distinct personality, so proposing to withdraw treatment is more traumatic. The decision has to be made in the child's 'best interests' but emotional, and possibly financial, interests may influence it.[16] Duff and Campbell argue for 'latitude' in the decision-making process since the families are the ones who 'must live with and are most affected by the decisions' so legal and medical guidance should only be generalistic.[17] Merrick notes that it has been openly acknowledged that 'treatment for babies with identical "selection criteria" could be quite different depending on the contribution from home and society'.[18] The question must be, is such variation acceptable? Possibly this represents a compromise that must be accepted, but only reluctantly, since no one can force parents to expend emotional and financial resources they feel unable to provide. Meyers suggests that parents, who may have 'different levels of tolerance and capacity to love and nurture such children', are 'responsible...for the financial and emotional burdens of nurturing and raising that child to take his or her place in society'.[19] Natural justice demands that each, within a given society, should have equal opportunity to benefit from treatment. However, inequality occurs naturally. No baby has a right to be born into a rich family or, even, a caring one; it is merely a matter of luck.

Moreno questions whether 'an infant's condition (is) ever so hopeless that all care, including feeding, should be withdrawn'[20] particularly since there is 'an offensive aspect of quality of life judgments that surfaces in the form of comparisons with 'normal' infants'.[21] He considers the 'notion of parental rights' untenable but support for the sanctity of life principle in the 'Baby Doe Rules' is only weak, because there are exceptions regarding the 'irreversibly comatose' and those for whom treatment is 'futile and inhumane'.[22] Unfortunately,

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[13]Caplan A, Blank R (Eds) *Compelled Compassion* 1992 Humana Press, Clifton, New Jersey at p255. Nothing has been found in researching this thesis that indicates a contrary view although it will be suggested that the input of others besides parents and doctors may be needed.
[14]Buchanan AE, Brock DW. *Deciding for others: the ethics of surrogate decision-making.* 1990 CUP, Cambridge at pp254-5.
[15]Stinson R. On the death of a baby. *J.Med.Ethics* 1981;7,5:5-18.
[16]It is worth noting that the British welfare system which pays out benefits to those who are disabled, such as mobility allowance, or attendance allowance for the carers, tends to discriminate against the under-five year olds by considering that nothing in terms of extra care is required than is required by a non-handicapped child of the same age. This can place an enormous burden on the parents of such a child: Mencap. Response to the Consultation Paper "Supporting Families". 1999 Mencap, London, www.mencap.co.uk accessed 27 January 2001.
[17]Duff R, Campbell AGM. Moral and Ethical Dilemmas in the Special Care Nursery. *NEJM* 1973;**289:**890- 895 at p894.
[18]Merrick JC. Critically Ill Newborns and the Law: The American Experience. *J.Legal Med.* 1995;**16:**189-209 at p195.
[19]Meyers D. The family and life and death decisions. In: Sutherland E, McCall Smith A (Eds); *Family Rights: Family Law and Medical Advance.* 1990 Edinburgh University Press, Edinburgh at pp59-77 at p71.
[20]Moreno JD. Ethical and Legal Issues in the Care of the Impaired Newborn. *Clinics in Perinatology* 1987;**14,**2:345-359 at p346. He cites several cases where, with the parents approval, a non-feeding policy was set in place by the physicians but later overturned by the courts. He describes (at pp351-2) how a 'telephone hot-line' number was displayed for a time in the 1980's in American neonatal intensive care units for anyone concerned that 'a handicapped infant was being discriminated against by being denied customary medical care or nourishment'.
[21]Ibid, at p357.
[22]Ibid, at p356.

he fails to discuss the fact that medical opinion prevails with differing, value-laden interpretations of 'futility'[23] and 'inhumanity''. To certain religions, sanctity of life is paramount over quality of life and withdrawing care to hasten death is 'inhumane' abandonment of the patient.[24] Eidelman relates how, in Israel, the rabbi's influence is more important than the doctor's in deciding whether to withdraw treatment with the future quality of life of the infant being no justification.[25] Alternatively, countries, like India, with widely-held beliefs in reincarnation, perceive no difficulties.[26] However, Indian preference for male children means '(d)ecisions to withhold or withdraw life support are usually undertaken earlier with regard to a female child than a male child'.[27]

Some doctors have prescribing habits which hasten death once a decision to withdraw treatment has been made.[28] However, it would be improper to withhold adequate pain relief because of fears of being accused of deliberately hastening death.[29] Most countries still believe euthanasia is unethical as well as unlawful.[30] However, there are differing attitudes to whether it is ethical 'to allow nature to take its own course'.[31]

Whitelaw and Thorensen have stated that '(a) decision to withdraw life support must be made on a certain diagnosis with the most up-to-date information available'.[32] Yet studies in the Netherlands have shown 'great variety in the criteria for life-shortening treatment'[33] with treatment withdrawal based on a 'diagnosis' of an 'unlivable life'.[34] Suggestions were made that scoring systems should be developed to decide which infants have 'unlivable lives' but these were rejected as capable of producing arbitrariness and subjectivity.[35] Whether they could be any more subjective than medical opinion currently appears is questionable but it is repugnant to think that any life could be reduced simply to a numerical value. The New Zealand report placed the interests of the child 'paramount' with decision-makers considering 'the burden of disability the child will carry'.[36] Third-party assessment of 'burden' can only be value-laden. Therefore, others suggest, the doctors' role should not extend beyond the provision of medical opinion.[37] This seems an appropriate limitation on medical prerogative. Establishing the neonate's 'best interests' requires clinical information and prognosis. Whilst the clinician may consider a certain prognosis carries a life not worth living, his/her views should not

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[23]See the discussion regarding futility in the previous chapter.

[24]For instance, Orthodox Judaism. See discussion of patient abandonment in the previous chapter and the discussion later in Chapter six regarding conjoined twins.

[25]Eidelman AI. Care of Critically Ill Newborns: The Israeli Experience. *J.Legal Med.* 1995; **16:**247-261 at p255.

[26]Subramanian KN, Paul VK. Care of Critically Ill Newborns in India. *J.Legal Med.* 1995; **16:**263-275 at p268.

[27]Ibid, at p274.

[28]The secrecy surrounding such habits means figures are impossible to obtain. In the Netherlands, one survey suggested that in 57% of neonatal deaths, treatment had been withheld or withdrawn earlier and in 23% of all cases, drugs were administered 'in doses that may have shortened life'. van der Heide A et al. Medical end-of-life decisions made for neonates and infants in the Netherlands. *The Lancet* 1997; **350:**251-5 at p252. This may over-state the situation since Huibers reports that only in 0.5% of cases was the life of the newborn intentionally ended and treatment had been withdrawn before death due to no hope of survival (31% of cases) and due to negative prognosis (19% of cases). Huibers AK. Beyond the Threshold of Life: Treating and Non-Treating of Critically Ill Newborns in the Netherlands. *J.Legal Med.* 1995; **16:**227-245 at p 230.

[29]It would also probably be held negligent behaviour on the part of the doctor as well and compensation could be sought under the civil law for failure to meet the standard of a reasonable doctor.

[30]The New Zealand Medical Association, for instance, holds that 'deliberately ending the life of the patient...even at the request of close relatives is unethical'. Blank RH. Treatment of Critically Ill Newborns in Australasia. *J.Legal Med.* 1995;**16:**211-226 at p215.

[31]For example, the Australian Medical Association considers that failing to operate on a Down's syndrome baby for a 'correctable defect' is merely allowing nature to take its own course: Blank, op cit n30 at p215.

[32]Whitelaw A, Thorensen M. 'Ethical Dilemmas around the Time of Birth'. In Gillon R (Ed). *Principles of Health Care Ethics* 1994 John Wiley & Sons, Chichester pp617-627 at p623.

[33]Huibers, op cit n28 at p234.

[34]Ibid, at pp238-240.

[35]Ibid, at p239.

[36]National Advisory Committee on Core Health and Disability Support Services. *Consensus Development Conference Report to the National Advisory Committee on Core Health and Disability Support Services* 1993 NACCHDSS, New Zealand.at p14. See also: Blank, op cit n30 at p217.

[37]Huibers, op cit n28 at p239.

take precedence over a real inquiry into what constitutes 'best interests'.[38]

4.1.2 The Critically Ill on Life Support[39]

Weir states that there are three categories of patient for whom intensive care may be indicated: (1) those whose probability of survival without...is low but whose survival with such support is highly likely;[40] (2) those who have a low probability of survival without intensive care support but who may have a higher chance of survival with it,[41] and (3) those who are at risk of becoming critically ill[42] and the monitoring facilities of the intensive care unit will ensure rapid assistance in the event of a sudden decline in condition.[43] However, the question of withdrawing treatment will eventually be raised. A pertinent factor is the effect the intensive care situation has upon patients, relatives and staff. Nurses are particularly under psychological pressure because of 'constant exposure to crises and death'.[44] Consequently, decisions are liable to be flawed.[45] Walton and Donen suggest categorising decisions to withdraw treatment in ICU[46] patients according to decision-maker: patients; families; doctors and lastly, the 'brain death cases'.[47] However, even with competent patients, conflict may arise if the physician disagrees. Walton and Donen suggest that conflicts can be resolved by discussion so 'one party or the other (or both, or neither) may modify his position and relax his resistance to the other's pressure'.[48] This fails to recognise the imbalance that exists between the different parties. Some physicians may be more willing to withdraw certain treatments than others and this can distort the decision-making process.[49] Different doctors, faced with the same patient, may make vastly different decisions about whether to withdraw treatment or institute a DNAR order.[50] The BMA recognises that resuscitating patients to preserve organs for donation, in the knowledge that this will provide no benefit to the patient, could compromise the principle of respect for autonomy but suggests only 'symbolic harm' is done.[51] The BMA relies upon gaining 'consent' from the relatives whilst acknowledging that such consent has no legal validity. This version of 'consent' is merely a convenient fiction enabling doctors to maximise treatment opportunities for others in the belief that this is ethically acceptable. This is very utilitarian. Surely, it can only be ethically acceptable to employ clinically

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[38]In support, see the discussion of the responses to the interview questions in the previous chapter and later in this one where several consultants indicated that ethical decision-making meant considering what they would want doing if the patient was 'their mother, sister, child...'.

[39]Adult critical care medicine includes coronary care units (where the patients are monitored, supported and resuscitated, if necessary, following a heart attack); medical intensive care units (which treat those with medical emergencies such as following heart attacks, drug overdoses and infective diseases); surgical intensive care units (where the patient is monitored and given ventilatory support etc. following major surgery); neurological intensive care units (which treat patients who have sustained brain damage) and burns units (treating patients who have sustained severe burn injuries). For the purposes of general discussion, these will not be separated.

[40]For instance, patients whose cardiac problems can be resolved by a pacemaker - a device that regulates the heartbeat which is often used in patients who have sustained cardiac damage to prevent future heart attacks (cardiac arrests).

[41]For instance, patients in septic or cardiogenic shock. Both are conditions that are potentially reversible with antibiotic or other therapy but left untreated are life-threatening and, because of the nature of such conditions, irreversible damage may have already occurred. For instance, the antibiotics may not be able to work fast enough to prevent the death of the patient but, if the patient can be sustained for long enough to enable the antibiotics to work, complete recovery may be possible.

[42]For instance, those who have undergone major surgery and may develop post-surgical complications such as a blood clot or pneumonia.

[43]Weir, op cit n2 at pp39-40. A variety of systems have been developed to choose who receives treatment in such units. For instance, the APACHE II system (Acute Physiology and Chronic Health Evaluation) uses a scoring system to categorise patients by severity of illness and the technological support indicated as necessary to sustain life.

[44]Weir RF, op cit n2 at p42. The unfamiliar surroundings and medicalisation and invasive technological support of their condition can also cause depression in the patients and their relatives and patients may develop infections and complications.

[45]For a discussion of how the behaviour of doctors can affect the way decisions are made see: Tilden RP., Tolle SW et al: Decisions About Life-Sustaining Treatment - The Impact of Physicians' Behaviors on the Family. *Arch.Intern.Med.* 1995;**155:**633-8.

[46]Intensive Care Unit.

[47]Walton DN., Donen N. Ethical Decision Making and the Critical Care Team. *Critical Care Clinics* 1986;**2,**1:101-9 at p101. In the last category, withdrawal of treatment presents no difficulty in countries that accept this concept such as Canada and the UK.

[48]Ibid, at p102.

[49]According to Christakis and Aasch, doctors are more willing to withdraw blood products and haemodialysis than antibiotics, feeding tubes or intravenous fluids: Christakis NA, Aasch DA. Biases in how physicians choose to withdraw life support. *The Lancet*, 1993;**342:**642-5 at p643.

[50]Cook DJ et al. Determinants in Canadian Health Care Workers of the Decision to Withdraw Life Support From the Critically Ill. *JAMA*, 1995;**273**,9:703-8 at p707. DNAR means Do Not Attempt Resuscitation.

[51]BMA. *Medical Ethics Today: Its practice and philosophy*. 1993 BMJ Publishing Group, London at pp27-28.

futile measures if the patient has given prior authority.[52] Otherwise, continuing treatment in a clinically dead patient[53] must be to subject that person to what would constitute battery in a living patient unless the underlying principle of state-provided healthcare is, as Raz suggests, one allowing public welfare to trump the interests of the individual.[54] 'Instead of essentially competing with the well-being of the individual, the common good (of society) is presupposed by it'.[55] Hence, the 'range and nature of common goods determine the options available to individuals in their lives'.[56] Whilst the interests of the state have not been expressly recognised as being relevant in this country, they have been used to support arguments in favour of continuing treatment in the U.S.A..[57]

Once intensive care treatment has been withdrawn, the patient is often transferred to a general ward[58] but the patient may stabilise leaving him/her in the condition which treatment withdrawal had hoped to avoid.[59] Three levels of care may be provided: minimally invasive; moderately invasive and maximally invasive.[60] The level selected depends on 'patient variables...;[61] physician variables...[62] and variables related to the technology itself...'.[63] Sometimes treatment is continued unenthusiastically.[64] Less effective treatment may be dressed up as 'doing everything possible' playing on patient/family ignorance. Such pretences are totally unethical and have helped to erode trust between patient and doctor leading to further difficulties in decision-making.

4.2 Outcome of Eventual or Probable Death

According to the BMA, doctors have a 'duty not to provide or continue treatment which they feel is not in the patient's best interests'.[65] This validates subjective, apparently unilateral, third-party assessments. Doctors are not always competent to decide patient best interests since these extend beyond the medical condition. The BMA suggests that the 'way in which the professional and society resolve the dilemmas posed by life or death cases reflects our most deeply held moral beliefs about the value of life and the qualities which make it valuable; the scope and limits of individual autonomy and the balancing of benefit for one patient with the possibility of causing harm to other patients'.[66] It suggests that 'society is prepared...to overrule the desires of some individuals in pursuit of a perceived wider public good'.[67] The BMA is, in effect, stating that doctors are the ones to decide whether to withdraw medical treatment; this decision should reflect their opinion of what is the patient's best interest; they can consider the interests of society or other patients and doctors have some

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[52]For instance, in the form of a signed organ donor card.
[53]Ie. brain dead.
[54]Raz J. *Ethics in the Public Domain.* 1994 Clarendon Press, Oxford, Chapter 1, 'Duties of Well-Being' at pp3-44.
[55]Ibid, p43.
[56]Ibid, at pp42-3.
[57]Weir, op cit n2 at p116 referring to *Custody of a Minor*, 375 Mass. 733, 379 N.E. 2d 1053 (1978) which held that the state had an interest in 'preserving the welfare of children, preserving life and protecting the integrity of the medical profession'.
[58]Lee DKP et al. Withdrawing Care: Experience in a Medical Intensive Care Unit. *JAMA* 1994;**271,**17:1358-1361 at p1360.
[59]Ibid.
[60]Weir, op cit n2 at p98.
[61]Listed as prognosis apart from intervention, patient preferences, effects of pre-existing concurrent conditions and availability of an ITU bed. It is submitted that the availability of an ITU bed does not constitute a factor relating to the individual patient in the same way the other factors listed do and it would seem more appropriate for it to be listed as a separate factor relating to hospital protocol or as an external resource allocation factor. Weir, op cit n2 at p41.
[62]Prior experience, prejudices, hospital protocol. Weir, ibid.
[63]Relative ease of intervention, cost, possible side-effects. Weir, ibid.
[64]For instance, dialysis may be introduced or continued but at a less effective interval than would be appropriate.
[65]BMA. *Medical Ethics Today: Its practice and philosophy*. 1993 BMJ Publishing Group, London at p149.
[66]Ibid, at pp150-151.
[67]Ibid, at p151. This can be linked to the earlier discussion regarding organ donation and the BMA approval of clinically futile measures being employed in order to preserve organs for donation.

sort of mandate from 'society' to put society's interests above the individual patient's when they consider it correct to do so. However, they refute any suggestion that societal interest could force physicians to assist patients to die since this would be to allow patient autonomy to impose upon medical autonomy and would predictably lead to a change in society's attitude towards the elderly, sick and disabled.[68] The BMA counsels doctors to practice medicine so 'life implies "benefit"' and 'death implies "harm"'[69] but there is a tension between this statement, designed to prevent doctors being forced into providing euthanasia,[70] and holding that death is 'in the best interests' of some patients.

4.2.1 Patients Reliant on Artificial Nutrition and Hydration

Patients may lose the ability, temporarily or permanently, to eat normally or sufficiently so artificial nutrition may be provided.[71] Some are mentally aware, others are totally unaware.[72] For the vegetative patient, court approval is necessary to withdraw treatment with decisions based on the patient's 'best interests'.[73] Regarding these patients, concerns have been expressed about the accuracy of the diagnosis.[74] Some have been misdiagnosed.[75] However, misdiagnosis occurs, sometimes through fault, often through lack of accurate data, with other patients so perhaps the vegetative patient should receive no special consideration on this ground.[76] For non-vegetative patients the decision to withdraw artificial feeding is rarely scrutinised by the courts.[77] Moreno considers continuing to feed a patient can cause 'protracted suffering' if other medical treatment has been discontinued and is tantamount to active euthanasia, for instance, if the patient has kidney failure since feeding leads to build up of toxins.[78] However, if a patient is being allowed to die from untreated kidney failure, is there really any ethical problem if that death is hastened by a few days as a result of toxaemia? Most patients in untreated end-stage kidney failure are comatose, so their ability to feel pain is minimal. A major concern

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[68]Ibid, at pp151-2.

[69]Ibid, at p154.

[70]Although some doctors consider it proper for doctors to assist patients to die if terminally ill or severely chronically sick. For instance, see the campaign of Jack Kevorkian in the U.S.A. where he was convicted of murder in March 1999 (he is appealing against his conviction) and also, in the U.K., the trial (*R v Moor* (1999) unreported) of a doctor accused of killing a patient with diamorphine who admits having 'helped' possibly 300 other patients die. Rose P. GP 'admitted he helped 300 patients to die'. *Daily Mail* 17 April 1999.

[71]Either by means of a feeding tube through the patient's nose into their stomach (nasogastric feeding) or by a tube directly into the patient's stomach (endogastric feeding) or by 'lines' (special tubes designed to go into veins) into veins in the patient's arm (peripheral intravenous lines - generally a temporary means) or by a 'line' into a large chest vein (total parenteral nutrition). The number of patients receiving some or all their nutrition this way in the States was estimated at about 1,404,500 in 1987: Mackay RD. Terminating life-sustaining treatments - recent US developments. *J.Med.Ethics* 1988;**14:**135-9 at p138. Artificial nutrition is very different from normal eating and has been classed as medical treatment by the British courts despite resistance from those who would argue that only the provision of medication should be considered medical treatment: *Airedale NHS Trust v Bland* [1993] AC 789. This is probably correct in that these are not methods of feeding a person that could be undertaken by the general public.

[72]For instance, in a persistent vegetative state like Tony Bland. This thesis intended to exclude patients with irreversible coma or vegetative state since the focus has been primarily upon situations where treatment could offer some benefit to the patient. However, the issue of withdrawal of nutrition raises similar concerns in both the vegetative patient and the stroke victim so it is appropriate to consider the best interests/quality of life/sanctity of life arguments in relation to the full spectrum of patients for whom this may be considered.

[73]*Airedale NHS Trust v Bland* [1993] AC 789.

[74]See: Andrews K, et al. Misdiagnosis of the vegetative state: retrospective study in a rehabilitation unit. *BMJ* 1996;**313:**13-16. His study found 43% of the patients referred to his unit had been misdiagnosed. See also, Smith S. The outer edge of consciousness. *Nursing Times* 1997;**93,**39:28-32 and The Multi-Society Task Force on PVS. Medical aspects of the persistent vegetative state. *NEJM* 1994;**330:**1499-1508.

[75]For two fascinating examples see: Goodwin C. Coma wife wakes after 16 years to find husband twice remarried. *The Sunday Times* 9 January 2000 and Hardy F. The boy who came back from the dead (the Geoff Wildsmith story). *Daily Mail Weekend* 17 November 1996. In some cases, the patient has been found to have conscious control over one muscle, for example, the ability to control blinking of one eye remains, and by utilising this to sound a buzzer to signify yes or no to questions, the patient can, labouriously, communicate with others: Smith S. The outer edge of consciousness. *Nursing Times* 1997;**93,**39:28-32 at p30.

[76]A diagnosis of PVS should not be made following traumatic injury until the patient has remained in a vegetative state for at least one year: The Permanent Vegetative State: Review by a Working Group Convened by the Royal College of Physicians and Endorsed by the Conference of Medical Royal Colleges and their Faculties of the United Kingdom. *J.Roy.Coll.Phys.* 1996;**30:**119. The courts will accept a diagnosis of PVS that has been made in accordance with these guidelines: *Practice Note (persistent vegetative state: withdrawal of treatment)* [1996] 4 All ER 766.

[77]Unless a challenge to the doctors' decision is made by an interested party or the decision to withdraw nutrition seems out of step with acceptable medical practice in which case criminal prosecutions or professional misconduct hearings might be contemplated. See, for instance: Horsnell M. Police check hospitals over 'backdoor euthanasia'. *The Times* 6 January 1999.

[78]Moreno JD, op cit n20 at p358.

of families is whether the patient will suffer as a result of starvation.[79] If the care the patient receives is reviewed holistically it may be possible to conclude that any shortening of life through continuing to maintain hydration and nutrition is outweighed by the benefit in not postponing death or the benefit in not suffering discomfort from hunger.[80] As Devettere points out, withdrawing artificial feeding does not mean the patient dies of the underlying medical condition - s/he dies of malnutrition and dehydration so the classification adopted (treatment or food) affects attitudes towards its removal.[81] Even groups who normally speak with one voice, such as Catholic bishops, are divided as to when and whether it is acceptable to withdraw artificial nutrition.[82]

The views of the family and the health care team may differ with some relatives believing cognisance is present. Smith enquires whether, when relatives insist that they can communicate after a fashion with the patient, 'even if we have not been able to prove it, who are we to say it is not there?'[83]

4.2.2 The Patient Reliant on Artificial Ventilation

Some patients have severe lung damage, possibly because of extreme prematurity of birth, occupational injury or smoking-related damage and initially temporary reliance can progress to permanent reliance, even though conscious and mentally aware.[84] Infectious disease may also be responsible.[85] The ethical issues can seem different from other treatments which, if withdrawn, lead to rapid death since the patient has 'personhood' potentially or actually present.[86] Others have major brain damage as well as requiring ventilatory support.[87] Ventilation now seems 'quite ordinary' treatment, not extraordinary, in countries like Britain[88] although the distinction was relied upon in *Quinlan*.[89] Hinging treatment-withdrawal decisions on distinctions between 'ordinary' and 'extraordinary' treatment is problematic since classification seems subjectively determined. Devettere argues death would take nothing of value from Quinlan and would cause 'no real social harm' so allowing death was not undermining society's interest in preserving life.[90]

Some patients, facing a 'locked-in' state, have petitioned the courts for recognition of their advance directives

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[79]This was a point considered in *Airedale NHS Trust v Bland* [1993] AC 789. For instance, it has been reported that it took an 85 year old woman two months to die after her feeding supplements were withdrawn and at the time of death she weighed only 25kg. 'Woman dies two months after food withdrawal.' *BMJ* 1997;**314:**1503. The GMC considered (regarding Ken Taylor, whom it suspended for six months) that a similar situation constituted 'serious professional misconduct'. *Bull.Med.Ethics* 1999;**146:**5.

[80]However, different religions and cultures may take a different approach to the question of whether death should be postponed at all costs. See the discussion in Chapter 6.

[81]Devettere R, *Practical Decision Making in Health Care Ethics: Cases and Concepts* 1995 Georgetown University Press, Washington DC at pp228-9. Devettere suggests adopting a new category for this procedure called 'medical nutrition'.

[82]Ibid, at p229.

[83]Smith S. The outer edge of consciousness. *Nursing Times* 1997;**93,**39:28-32 at p31.

[84]The number of patients in the States receiving ventilation in 1987 was between 3,775-6,575: Mackay RD. Terminating life-sustaining treatments - recent US developments. *J.Med.Ethics* 1988;**14:**135-9 at p138. Many of these will not be conscious but some are. Mackay reports (at pp135-6) one such case where the patient, having agreed to a trial of ventilation, was unable to persuade the doctors to remove the respirator without court approval. She died waiting for that approval.

[85]For instance, neurological damage following meningitis or polio may damage the centre of the brain which controls breathing leading to permanent reliance on artificial ventilation. The polio epidemic of the 1950's left many people dependent upon the recently invented 'iron lungs'. Some patients have lived forty years or more in such a condition.

[86]The ability of some 'patients' reliant on ventilation to lead active and worthwhile lives can be quite amazing. For instance, the 'Superman' star, Christopher Reeves, now ventilator dependent and quadraplegic is actively campaigning to generate funds for research and facilities to help paraplegics overcome their injuries: Christopher Reeve Paralysis Foundation, website address www.apacure.com. Accessed 27 January 2001.

[87]Like Karen Quinlan: *Re Quinlan* (1976) 50 N.J. 10. Ventilation was held 'an extraordinary means of preserving life' hence not required by the Catholic faith of the family.

[88]Devettere, op cit n81 at p167. There are many cases of people receiving long-term ventilatory support following spinal injuries or motor neurone disease.

[89]*Re Quinlan* (1976) 50 N.J. 10.

[90]Devettere, op cit n81 at p172.

to ensure that the doctors treating them will not implement ventilatory support indicating that they fear doctors will insist on preserving 'life' irrespective of their wishes.[91] An interpretation of professional ethics which leads to such cases must be flawed. Is it because the doctor knows the 'person' who is still present so cannot handle the guilt/frustration/grief at being unable to prevent loss of function? Is it fear of sanctions? Sometimes terminally ill, autonomous patients have been restrained to prevent them removing ventilator tubes.[92] Such practices surely represent overtreatment.

4.2.3 The Patient Reliant on Dialysis

Patients who would have died from kidney disease as young adults have grown old receiving dialysis. Through ageing, other problems develop and withdrawal of dialysis may be considered.[93] When should this be considered and should the greater benefit others might gain from using the often scarce resource of a haemodialysis machine be regarded? One study found considerable variability amongst dialysis unit medical directors regarding whether to continue dialysis.[94] Most would consult with the patient's family and a small minority would provide dialysis if that was what the family wished even though they felt it medically inappropriate.[95] Dementia seems the most common cause of dialysis withdrawal and 'nephrologists are more comfortable in making decisions to stop dialysis for patients with Alzheimer's disease than other conditions'.[96] This suggests that patients should have some awareness of the benefits provided by the medical intervention. Clearly, dialysis *per se* is not medically futile since it achieves its aims, yet ethicists seemingly accept the futility argument in such situations.[97] This approach should be challenged since many other medical interventions are implemented or continued regardless of patient awareness at the time or future ability to be aware of the benefit gained. To accept it is to accept that medical treatment is only appropriately directed towards those with 'personhood' or potential to develop 'personhood'. In the U.S.A., guidelines have been called for to exclude or remove from the Medicare Program those with 'limited life expectancy and relatively poor quality of life' since the 'existence of a public entitlement does not obligate physicians to provide dialysis to all patients with renal failure'.[98] Quality of life assessments generally emphasise 'personhood'.

4.2.4 The Patient with Cancer

The search for cancer cures has produced a plethora of alternatives.[99] Often, if the first drug or combination therapy fails, an alternative can be tried, sometimes several times before defeat is admitted. Stoll points out

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[91]See, for instance, the Annie Lindsell case (withdrawn prior to judgment): Lindsell A. Why I believe I should have the right to die. Daily Mail 18 September 1996 and The Lords Hansard Text for 6 May 1998 (980506-12) Columns 707-726 www.parliament.the-stationery-office.co.uk/pa/ld199697/ldhansrd/pdvn/lds98/text/90506-12.htm accessed 8 January 2001.

[92]See, for instance, Devettere's description of the case of William Bartling, 70 years old, hospitalised 6 times in the previous 12 months with lung cancer and severe emphysema (a condition that makes breathing very difficult and requiring the patient to breathe pure oxygen) yet, despite writing notes that he did not want ventilation (since he could not talk due to the tube in his throat) he was tied to his bed. Devettere, op cit n81 at pp177-9.

[93]For instance, the patient may suffer a 'stroke' or develop pre-senile dementia or cancer.

[94]Moss AH et al. Variation in the Attitudes of Dialysis Unit Medical Directors Toward Decisions to Withhold and Withdraw Dialysis. *J.Am.Soc.Nephrology* 1993;**4**,2:229-34. The study was conducted by means of a questionnaire circulated to the medical directors of a random sample of adult dialysis units throughout the United States and 318 replies were received. 32% were prepared to withdraw dialysis and 68% would continue it. Dialysis in such patients in the U.S.A. has normally been privately funded during adult (working) life.

[95]Ibid. Moss found six of the 318 medical directors consulted were prepared to give treatment in these circumstances. This is perhaps not surprising given that doctors are possibly more likely to practice defensive medicine in the U.S.A. because of fear of litigation.

[96]Ibid, at p232.

[97]Schneiderman LJ et al. Medical futility: its meaning and ethical implications. *Annals.Int.Med.* 1990; **112**:949-954.

[98]Moss AH, op cit n94 at p233.

[99]Certain types of cancer are recognised in themselves as terminal events and consequently incurable. Metastases which develop as a secondary or late form of cancer fall into this category on the whole although some are unusual in being sensitive to chemotherapy.

that doctors are under pressure to 'examine their management decisions' and are forced by rationing and queuing to 'choose between patients on both medical and social grounds'.[100] He believes curable cancers are relatively uniformly treated throughout the developed world, but patients with advanced cancers 'may be offered vastly different treatments' due to 'differences in value judgements as to what is appropriate'.[101] Such variation based solely upon a doctor's subjective opinion seems unjustifiable. The same patient could be offered further 'curative' treatment by one doctor whereas another doctor would recommend withdrawing from treatment and adopting the palliative model of care. The doctor's workload, departmental resources and stress levels may all be influential. Regional variations in curing cancer are of major public concern in Britain.[102]

Moving from the curative model of treatment to the palliative one is always difficult. It is particularly emotive when the patient is a child. 'Child B' received much media attention yet other children might indicate that they are ready to have chemotherapy/radiotherapy withdrawn. The BMA considers it is 'ethically justifiable' to continue treatment against a child's wishes if there is a good chance that it will save life or prevent 'serious deterioration in health'[103] but they also recognise that it may be appropriate to defer to his/her wishes where s/he has the requisite understanding.[104] However, the child, though of reasonable maturity, may not be enabled by those caring for him/her to express his/her viewpoint[105] and even if s/he can, the treatment refusal may be overridden.[106] Relatives, and sometimes patients, desperately 'clutch at straws' in the hopes of a miracle so some doctors continue with aggressive therapy that is no longer appropriate.[107] Stoll suggests the doctor's options regarding continuing curative treatment should be limited by guidelines reflecting society's interests in containing costs.[108] The Commission for Health Improvement and NICE will have increasing importance in the area of cancer treatment. New drugs are being screened for clinical and cost effectiveness and guidelines on their use are being developed.

4.3 Outcome of Reduced Quality of Life

For many patients, death is distant yet their quality of life is markedly reduced even though medical science could produce improvement by reducing pain, immobility or mental disintegration. Several reasons for the withdrawing of treatment options from various patient groups can be postulated. It may be because they are unequal partners in the healthcare relationship, or because of resource allocation decisions by purchasers. Certain groups may simply be less-valued by society.

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[100]Stoll BA (Ed) *Ethical Dilemmas in Cancer Care*. 1989 The Macmillan Press Ltd, Basingstoke at p3.
[101]Ibid, at p20.
[102]Department of Health. *Saving Lives: Our Healthier Nation.* (Cm 4386) July 1999 The Stationery Office, London.
[103]BMA. *Medical Ethics Today: Its practice and philosophy*. 1993 BMJ Publishing Group, London at p77.
[104]Ibid, at p78. The legal position of minors will be considered in Chapter 6. The common law position is that, in general, minors who are '*Gillick*' competent may consent to treatment, but are unable to refuse medical treatment (*Gillick v West Norfolk and Wisbech AHA* [1986] AC 112). Any such decision to withdraw potentially life-saving treatment at the request of the minor should require the approval of the courts.
[105]Ackerman and Strong describe such a situation involving a terminally-ill adolescent girl whose mother was pushing for continuing aggressive treatment. The options open to the physician are described as (1) to continue aggressive treatment; (2) to continue aggressive treatment but continue to try to change the mother's mind; (3) to taper off treatment without telling the mother or the child; (4) to open discussions with the patient without her mother's knowledge and expressly confront the child with the knowledge of her impending death; (5) to talk to the child without her mother's knowledge and attempt to find out if the child wished to discuss her illness or (6) wait until all the family was gathered in the child's room and introduce the subject. Ackerman TF, Strong C. *A Casebook of Medical Ethics* 1989 Oxford University Press, New York at p52.
[106]See, for instance, the cases of *Re W (a minor) (medical treatment)* [1993] Fam 64; *Re R (A Minor)(Wardship: Consent to Treatment)* [1992] Fam 11 and *Re E (A Minor)(Wardship: Medical Treatment)* [1993] 1 FLR 386 which are discussed more fully in Chapter Six.
[107]Stoll BA (Ed) *Ethical Dilemmas in Cancer Care*. 1989 The Macmillan Press Ltd, Basingstoke at p20.
[108]Ibid, at pp24-6.

4.3.1 The Patient with Dementia or Mental Illness

Dementia is a condition where the rational balance of the mind has been lost, permanently or temporarily.[109] Originally a condition of the elderly, premature dementia is now seen in young patients.[110] Some patients suffer from a combination of mental handicap, mental illness and/or dementia in addition to their physical ailments.[111] The younger the patient, the more difficult it is for the permanence of mental incapacity to be accepted by family/carers. Conversely, it is submitted, the older the patient the more commonly s/he is assumed to be incompetent.[112] The government has recently agreed that there should be a rebuttable presumption of competence.[113] Callahan believes curative or acute care is only appropriate for those with 'personhood' so when the patient loses this, the primary goal of healthcare should be palliative rather than attempting to cure whatever physical health problems they have.[114] He fails to address the difficulties in assessing 'personhood' in the demented patient unlike the patient in persistent vegetative state or the anencephalic baby.[115] Likewise, age differences between the elderly patient and the physician[116] as well as the environment of care cause problems.[117] Thomasma, similarly favouring 'personhood', believes it preferable to rely upon informally expressed values of the patient when deciding to withhold and withdraw treatment rather than having to rely upon advance directives.[118] It seems to be the role of the family to supply the doctor with accounts of these 'values'. This reflects how treatment plans are currently devised. Accounts of the patient's values may not only include views about whether the patient would want to live as long as possible or would wish to die if his or her faculties went but may contain a sub-text regarding financial values. Patients may be afraid of their children's inheritance being destroyed by residential home costs. The relatives advising the doctor may have the same concerns.[119] Benefits payable under insurance policies may be affected.[120]

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[109]Senile dementia of the Alzheimer type affects 4-5% of those over 60 years old: Anon. *Donezepil in the treatment of mild to moderate senile dementia of the Alzheimer type.* Evidence-Based Purchasing Report No 69 The Wessex Institute for Health Research and Development. June 1997.

[110]In some of these cases, the dementia is attributed to 'new variant' Creutzfeld Jacob Disease which, it is believed, is linked to the cattle condition, Bovine Spongeform Encephalitis. In other cases, the dementia or mental illness may arise in young to middle aged adults as a result of unusual infections of the brain tissue as a result of the weakening of the auto-immune system, for instance, as a result of AIDS (Auto-Immune Disease Syndrome) or as a result of chemotherapy or drug abuse.

[111]Each of these conditions will have its own effect upon the ability of the patient to participate in the decision-making process. One person whom the author knows was born with a learning disability, was diagnosed as schizophrenic in her 20's and has recently, at the age of about 50 years, been diagnosed as having early dementia. See also, van Thiel GJMW et al: Retrospective study of doctors' 'end of life decisions' in caring for mentally handicapped people in institutions in the Netherlands. *BMJ* 1997;**315:**88-91.

[112]Carmel S. Medical Students Attitudes Regarding the Use of Life-Sustaining Treatments for Themselves and for Elderly Persons. *Soc.Sci.Med.* 1998;**46,**4-5:467-474 at p468. Carmel found that medical personnel negative stereotyped the elderly and this caused more problems in the decision-making process than their lack of communication skills.

[113]Lord Chancellor's Department *Making Decisions.* October 1999 The Stationery Office, London. See also: de Wachter, ter Meulen. Dementia Research: ethical issues of research with cognitively impaired elderly subjects. *Biomedical and Health Research* Newsletter 1996;7,1:5-6. European Commission DGXII Science, Research and Development.

[114]Callahan D. Dementia and appropriate care: allocating scarce resources. In: Binstock RH et al (Eds): *Dementia and Ageing: Ethics, Values and Policy Choices.* 1992 The John Hopkins University Press, Baltimore at pp141-152. Also cited by Campbell A et al, *Medical Ethics* 2nd Edn. 1997 Oxford University Press, Oxford at p149.

[115]There is a poem, written by a 'demented' patient who had not communicated in months with anyone although she was occasionally seen to write on scraps of paper, which seems to sum up the way total incompetence is often assumed: 'I'm an old woman now and nature is cruel, 'Tis her jest to make old age look like a fool... But inside this old carcase a young girl still dwells...So open your eyes nurses, Open and see, Not a crabbit old woman, look closer - see ME'.

[116]For instance, Carmel has reported that medical students consistently rated the desire of elderly patients to live much weaker than their own. This she explained as primarily due to differences in attitude towards death and strength of religious belief. Carmel S. Medical Students Attitudes Regarding the Use of Life-Sustaining Treatments for Themselves and for Elderly Persons. *Soc.Sci.Med.* 1998;**46,**4-5:467-474 at p471.

[117]Many elderly patients have been found to be suffering from malnutrition and this has contributed to the loss of mental function which can be restored (Smith S op cit n83 at p31) Also, it has been found that providing some 'demented' patients with the sort of surroundings, food, music etc that they were familiar with in their young to middle years can be useful in re-orientating them to their surroundings and day centres often carry out this approach.

[118]Thomasma DC. 'Mercy killing of elderly people with dementia: a counterproposal'. In: Binstock et al, op cit n114 at pp101-7.

[119]A number of the cases of 'bed-blockers' are due to patients who are too dependent to be sent home but whose family will not arrange for them to go into care. Tony Blair recently told Alice Miles who was conducting an investigation into the NHS that his government will replace the convalescent home beds scrapped twenty-five years ago: Miles A. Can the NHS be Saved? Last Chance. *The Times* 26 May 2000.

[120]With term insurance, death has to occur within the term of the insurance period. Most policies refuse to pay out if the patient has committed suicide. It is possible that some insurers may consider an Advance Directive which, when complied with led to the death of the patient, is equivalent to suicide.

4.3.2 The Elderly Patient

Certain conditions are seen particularly as conditions affecting the elderly, for instance, 'strokes'[121] which may leave the patient with varying degrees of paralysis and/or aphasia.[122] Provision of effective and aggressive treatment, particularly speech and physiotherapy which can reduce disabilities considerably, is patchily provided throughout the U.K. and, if provided, is frequently withdrawn after a short period thus preventing the fullest possible recovery.[123] Also, elderly people are more likely to have age-related chronic conditions such as arthritis, coronary artery disease and dementia. Because of these multiple pathologies,[124] decisions to withdraw active treatment may be made earlier than with younger patients or one with only one clinical problem. Patients may be designated, Not For Resuscitation, even though there is no evidence that attempting resuscitation would be futile or unwanted.[125] Buchanan and Brock consider that age itself should not be 'equated with loss of competence and, where the patient is competent, s/he should be involved in the process of deciding whether to withdraw treatment or not.'[126] Concerns have been expressed that treatment is withdrawn (or withheld) because of age rather than ability to benefit.[127] An example of this is when a decision is made not to treat an iatrogenic pneumonia in a demented patient. Such a decision is properly seen as withdrawal of treatment even though it is a new course of antibiotics which is needed because it is part of a continuum of care. The less confident a physician is over such a decision the more likely he or she is to consider the wish of the family or nursing staff to treat the patient curatively.[128] However, there is some evidence of a move away from considering the role of the family legitimate.[129]

4.3.3 Other Conditions

Sometimes the duration of treatment may be restricted due to the costs involved. Few healthcare purchasers fund in-vitro fertilisation treatment at all and those who do often limit the number of 'cycles of treatment' after which treatment is withdrawn.[130] This is an area of inequality and injustice which desperately needs resolution.[131]

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[121]The correct medical terminology for a 'stroke' is cerebrovascular accident. The damaging effects occur when a portion of the brain is damaged by bleeding into the tissues or occlusion of the blood supply. In fact, despite the presentation of 'strokes' as a problem of the elderly, the most common age to suffer from one is between 40 and 55 years. For a general discussion of the pathology of ageing and the implications for medical ethics see Campbell A. *Medical Ethics 2nd Edn*. Oxford University Press, Oxford at pp136-152.

[122]Aphasia is an inability to speak or to talk in a coherent manner. Understanding is present but the ability to communicate so others understand is absent.

[123]This is an area where the voluntary sector has begun to provide therapy and support to try to fill the gaps in provision nationwide or the limited amount of provision given. Stroke is one such charity dedicated to helping victims of strokes with volunteers providing speech therapy and exercise classes.

[124]This is the term used when a patient has more than one illness or medical condition for instance, where a diabetic patient has gangrene and also has suffered a stroke.

[125]For instance, in one case heard by the Ombudsman, an elderly woman admitted to hospital with bronchopneumonia was designated Not for Resuscitation and the DNAR order remained in her notes for five days during which she made a good recovery before her son found out what it meant. She recovered fully from her illness. Select Committee on the Parliamentary Commissioner for Administration *Minutes of Evidence* 13 November 1991 HMSO, London at pp23-28.

[126]Buchanan & Brock, op cit n14 at pp268. Also, it should be remembered that incompetence can be temporary, for instance, due to medication.

[127]Ann Winterton's Medical Treatment (Prevention of Euthanasia) private member's bill presented to Parliament in January 2000 attempted to address these fears through legislation but failed for a lack of support and parliamentary time.

[128]van der Steen JT et al. Decisions to treat or not to treat pneumonia in demented psychogeriatric nursing home patients: development of a guideline. *J.Med. Ethics* 2000;**26:**114-120 at p117.

[129]See: Craig VJ. Patient decision-making: medical ethics and mediation. *J. Med.Ethics* 1996;**22:**164-7, in particular, at p165.

[130]Anon. Who should pay for test tube babies? *Woman's Weekly* 11 June 1996. For instance, it was reported that Morecombe Bay HA would only fund one cycle (attempt) per patient which dramatically reduces the chances of succeeding in producing a live baby. It should be remembered that the number of pregnancies achieved by IVF is far greater than the number of 'take home' babies.

[131]The present government pledged, in 1998, to eliminate regional inequalities in treatment opportunities over a ten year period. *A First Class Service* paras 1.6, 1.9. July 1998 The Stationery Office, London. The National Institute of Clinical Excellence (NICE) has recently started evaluating infertility treatments: NICE. Press Release: *Response to announcement regarding Infertility Guidance*.30 November 2000, www.nice.org.uk/article.asp?a+12826 accessed 5 January 2001.

Occasionally, a situation may arise when withdrawing treatment is considered because of failure to co-operate and/or abusive, aggressive or inappropriate behaviour during treatment. Ackerman and Strong describe a situation where a young adult male with low I.Q. and criminal convictions refused to co-operate with leukaemia treatment. Initial agreement would be followed by refusal once treatment commenced. He was abusive and aggressive towards nursing staff. He could give no reason for his behaviour and understood his need for treatment.[132] The question arises whether treatment which is necessary to prolong life or save life can be withdrawn in such circumstances. If the patient is viewed as fully autonomous, his behaviour could be construed as non-verbal refusal of treatment overriding his prior verbal or written consent. It may seem appropriate to hold that the patient is not acting autonomously since no reasonable person would behave like this having balanced the risks and benefits of treatment against the outcome of non-treatment. Irrationality of decision or behaviour is insufficient evidence of a lack of competence.[133] The difficulty of enforcing treatment which necessarily continues over a number of weeks or months means healthcare staff would be at risk of patient violence.[134] This raises the issue of respecting the autonomy of the care provider who could be forced, into providing care in a situation exposing him or her to risk. To enforce an obligation to provide care in such a situation would be to oblige healthcare staff to accept risks beyond the call of duty.[135] Mental health staff, particularly nurses, face similar violence. Just because people are being treated for mental illness does not mean that they lack autonomous control over their actions.[136] However, duties of care towards patients make it difficult to withdraw further treatment.

In other situations, such as long-term rehabilitation following traumatic injury, the patient may feel that he or she is being 'bullied' by healthcare staff to produce the little bit more each day that is necessary to maximise recovery. Such patients will argue that they wish to be left alone, they can't take any more. This may be founded upon an irrational belief as to their own capabilities which Savulescu would suggest is evidence of incompetence overridable by the professional.[137]

4.4 Empirical Research Analysis

This section will analyse the responses given by the eighty-five consultants interviewed to the following questions[138]:

> *Regarding the individual patient, when deciding to withhold or withdraw certain treatments, what sort of criteria do you use and which criteria should not be used?*

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[132]Ackerman & Strong, op cit n105 at pp9-12.

[133]*St George's Healthcare NHS Trust v S.* [1998] 2 FLR 728. This case, and others which raise issues of irrationality, is discussed later in this thesis.

[134]A situation which could certainly be envisaged in this country would be where a minor, under the age of eighteen years was compelled to accept medical treatment against his or her own will. Many teenagers are of sufficient size and aggressive nature to cause a lot of damage to persons and property were they to be subjected to medical treatment contrary to their wishes albeit in accordance with the law.

[135]When the courts place an obligation to treat a reluctant patient upon a hospital or medical team, it might be possible for the hospital as employer to refuse to allow its employees to be exposed to risks of injury since it has statutory duties to avoid harm befalling its employees, for instance, under the Health and Safety at Work etc Act 1974 as well as obligations under the common law.

[136]The government has launched a Zero Tolerance campaign to stamp out violence against healthcare staff. Department of Health. *We don't have to take this. Resource Pack.* L20/002 November 1999. DoH, Wetherby.

[137]Savulescu J, Momeyer RW. Should informed consent be based on rational beliefs? *J.Med.Ethics* 1997;**23:**282-8 at p282.

[138]A list of the consultants, maintaining confidentiality, can be found in Appendix A. The consultants were based at four different hospitals (A - D), and were from a variety of specialties. A descriptor of the hospitals, maintaining confidentiality, can be found in Appendix B.

Who should be involved in the decision to treat/not to treat a particular patient?

Do you think relatives should have a say?

4.4.1 Criteria used in deciding to withdraw certain treatments

As discussed in the previous chapter a variety of factors were identified.[139] The data will be analysed utilising the same themes as before.[140] Fear of legal sanction was a new criterion identified regarding treatment withdrawal which was not raised regarding withholding treatment. All those who mentioned patient merit rejected it as unethical. However, regarding financial costs and patient age, there was disagreement over whether they could legitimately be included as part of the decision-making process. There was also an identifiable difference in approach to 'the wishes of the family' as a criterion. Although it had been rejected with regard to withholding treatment, several consultants felt it was an appropriate criterion in regard to withdrawing treatment.[141] Surgical consultants were rarely involved in withdrawal of treatment decisions. Their involvement in such cases was generally more peripheral, such as when a patient was not for active treatment but a surgical intervention such as re-siting a feeding tube was proposed.

4.4.1.1 Effectiveness of treatment

This seems the most important criterion and typical comments included:

> *The thing that is major for me is turning off ventilators. We decide to do that when treatment is no longer effective.* D6

Difficulties arose when it was impossible to accurately gauge the effectiveness of treatment or it was less successful than predicted:

> *There was a lady on ITU. She was about 80...on holiday and fell ill. She just got worse and worse and her kidneys stopped working so I took the relatives to one side and said, look, we've really reached the end. We can't dialyse someone who's in this condition. The relatives were very accepting...and we turned everything off and she got better...You have to accept that if you make decisions they could be wrong.* A5

> *We've had some patients who have had heart surgery and for some reason have had a cerebral event so we have had to withdraw medication and gradually wean them off the ventilator.* B3

Infrequent contact with the patient probably makes predicting outcomes and assessing quality of life difficult

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[139]The criteria included: a) treatment clinically ineffective; b) the patient's quality of life; c) balance of burden greater than benefit; d) wishes of patient (including those expressed in advance directives); e) wishes of the family; f) the patient's social circumstance; g) financial costs; h) burden on the family; h) burden on healthcare staff; i) the patient's age; j) merit of the patient; i) fear of legal sanction.

[140]The themes selected are: Effectiveness of treatment (which could have included quality of life and patient age); Quality of life (which could have included the Balancing of Benefits and Burdens); Balance of Benefits and Burden; Patient Wishes; Family Wishes; Burden on the Family/Carers; The Burden on Healthcare Staff and Resource Implications.

[141]Except in regard to new-born babies with congenital short bowel syndrome or similar conditions where, despite the best efforts of science, the baby would still die within months. In those cases, where a 'best interests' approach did not make the decision to treat or not to treat fall one way or another, the parental wishes were seen as an acceptable way of making the decision.

but none of the consultants questioned their own practice over this:

> *The problem is, old people with multiple diagnosis can be unpredictable...we go round the patients twice a week and on those occasions review the CPR decisions as we go.*[142] *We rarely change them but sometimes we do.* A22

Despite recent legal cases supporting the fact that artificial nutrition and hydration is medical treatment and can be withdrawn to allow the patient to die,[143] not all consultants seem happy to do this:

> *When it becomes someone whose treatment is futile, you're not obliged to give futile treatment. You give basic medical care which I see as food and drink but you don't give anything else.*[144] A31

4.4.1.2 Quality of Life

For many, this was the deciding factor as to whether treatment should be continued particularly once it was apparent that things were not progressing well. Some consultants take a more subjective approach to patient quality of life than others:

> *I may have a view that life isn't very good for the patient but if their view is that it is pretty darn good, they go on having treatment.* A21

> *Life can still be sweet even if all of a sudden you're suddenly disabled....In terms of futility, I think we're probably the best judges of futility. I think you should still go and discuss that with the patient, even if they say, 'If you do something which will put me through a lot of discomfort, I might live an extra three or four months...(but) actually my son's wedding is coming up and I want to go there.' Now that to me means a lot.* A22

It was clear some consultants were less comfortable discussing 'end of life' decisions with patients than others and this could lead to a more objective, less patient-centred approach being taken. Constraints on beds and other resources could influence how the patient's quality of life was assessed:

> *I use clinical criteria for patients, usually their best interests (but).you have to temper clinical decision-making with resources.* A20

4.4.1.3 Balance of Benefits and Burdens.

Several doctors mentioned that the impetus for withdrawing treatment often came from the nursing staff. The general impression was that this was because they were closer to the patient and more involved with the relatives. The burden of the treatment was often seen as greater when an old person was concerned since the potential benefits of living longer were reduced. A typical comment was:

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[142]He was referring to the decisions to withhold resuscitation.
[143]See: *Airedale NHS Trust v Bland* [1993] AC 789.
[144]Discussing a case of severe brain damage, amounting almost, but not quite, to brain-stem death. It was clear from other parts of this interview that 'food and drink' included tube-feeding.

That would be my experience, that nurses often want to withdraw treatment sooner than doctors and the issue will often be raised by them - are we doing the right thing? - so I think it comes from the team and you always discuss it with the family, you would never do it unilaterally, the family have to agree. A2

The interviews with consultants who cared for children showed that withdrawing treatment from a child was always hard. They all used the language of withdrawing treatment 'in the best interests' of the child when the benefits of continuing treatment were outweighed by the burdens.

I think every child is individual so that's hard...In terms of withdrawing intensive care...providing you have got the principles right, we are clear, we can do this, not often, but when we do it's because we perceive it as being in the child's best interest. B11

In contrast, it seemed that concluding that treatment was too burdensome to continue in the case of elderly adults was easier. Other typical comments were like the following which seems, with hindsight, to confirm fears that the lives of old people are being deliberately ended by the withdrawing of artificial nutrition:

Cases like the Bland case, I think they have bought the debate into the open, but when you are dealing with old, frail people who are at the end of their life anyway these things are happening much more commonly and it is impossible to consider that you are going to get judicial review on every case. It just won't happen. D9

4.4.1.4 Patient Wishes

It was recognised that inherent factors, individual to each patient, would influence whether the patient wished to withdraw from treatment. 'Fighters' would opt to continue, and would cope with the difficulties of treatment. This fighting spirit as an influence on the decision-making process was even extended to babies:

One of our staff has given birth to a 400 gram baby...there are many other babies who come out at 400 grammes who are black and blue in the face and have no hope of surviving. I think the baby makes the decision. A12

Withholding and withdrawing are quite different issues...to take withdrawing treatment, the major thing is what the patient actually wants. You can't withdraw a patient from treatment without discussing it with them. A21

There are occasions when it's terribly important that somebody lives an extra few months. A26

Difficulties could arise when the treatment withdrawal was requested by the patient but the clinician believed it could still be effective. Failing to accede to the wishes of a competent patient to discontinue treatment is to act paternalistically, representing a failure to acknowledge the paramountcy of patient autonomy and the validity of the patient's own values:

I would feel very uncomfortable withdrawing treatment even if the patient wished to do so unless I felt that was right because the prognosis was bleak...You can see this as tantamount to suicide, the

act of withdrawing dialysis treatment kills the patient, or allows the patient to die, but you can see it as stopping artificial prolongation of life.[145] A30

It was sometimes necessary to balance patient expectations against financial reality. Several consultants mentioned the drug, Taxol, which was being hyped by the media as a wonder drug for end-stage breast cancer.[146] The local health authority would not fund it. The comments seem to indicate that not only were the public being misled about it being a financial decision only (and their information would come from the media who receive it from the drug companies), but they were being misled as to whether it was always the best drug for the individual to receive. Of course, it is possible that what was related was simply a comforting storyline for both the patient and the consultant:

I know I'm not able to offer Taxol for patients with ovarian cancer or breast cancer but I offer an alternative drug which I personally believe isn't that much worse. It may not be quite as good but the difference in my view is not a major issue. The drug I'm using is much easier for the patient to tolerate than Taxol so I think there is a trade-off there. C5

4.4.1.5 Family Wishes

The wishes of the family came across as important in withdrawal of medical treatment because, usually, there has been time for the patient and/or family to build up a relationship with the healthcare team. The consultants seemed to feel responsible for the welfare of the family as well as the patient. Sometimes clinical evidence indicated curative treatment should be discontinued on grounds of futility and palliation started but treatment would continue because the patient or the relatives were not prepared to accept death.

I treat for the psychological benefit as opposed to the physical one. I hate doing that. C4

There are two important aspects, one is the medical side, the medical decision, the medical prognosis. The second is the family. What the family thinks. I try to carry out my practice in such a way that there's good communication channels open. But obviously when a family want us to carry on in the face of hopelessness one tries to explain to them. B4

There was one occasion where a mother was just not going to accept that her son was dying until he was actually dead. What we did on ITU was just prolonging his life. The rest of the family were aware of it but we were doing this futile treatment for her to help her come to terms with it. A11

It was obvious that continuing treatment in such circumstances was felt to be wrong. Since clinical effectiveness seemed the paramount factor in most of the consultants' decision-making process, ignoring this was seen as unscientific and burdensome on hospital resources and staff. This indicated that there could

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[145]Similar difficulties have been faced by doctors when patients have refused Caesarean sections to save their or their baby's life. None of the consultants interviewed indicated ever having been in that sort of situation. The refusal of Caesarean section cases will be discussed in Chapter 8.

[146]At the time of conducting the interviews there was a national media campaign advocating the cause of a young woman who was dying from breast cancer and who 'wished to have Christmas with her infant children'. Taxol was said to cost £10,000 per patient per annum. NICE has now agreed it should be used in the case of ovarian cancer: NICE. Guidance on Taxones for Ovarian Cancer. NICE 2000/013. Issued 5 May 2000 The Stationery Office, London. However, the consultant's remarks regarding patient tolerance of it are important to note. The media can be manipulated by drug companies into marketing their products for them when possibly it is not the most suitable drug for all patients.

possibly be a balancing process between the needs of the family and the burden on the healthcare staff/financial resources.

In other cases, treatment was not clinically futile, but the probability would be that, although the patient's life would be saved, s/he would be left severely handicapped. Several consultants spoke of continuing treatment as a result of family wishes even though the clinical evidence was that the patient (often a child) would be severely handicapped if they did survive:

> *There have been some situations, and I can recall 2 or 3, where we have said to parents look, we think he's not going to survive, but if he does survive he will be severely handicapped and we feel we should stop treatment. They have said no, and we've continued treatment and the child has survived and has been severely handicapped. Now it sounds horrible to say it, but that is a bit of a comfort to me because it shows that my criteria for saying a child is going to be severely handicapped are probably correct. One always worries about that.* A12

4.4.1.6 Burden on the Family

The anticipated burden on the family could have an effect on whether the recommendation would be to continue treatment or not:

> *The relatives (should be involved) if it's going to have implications for them.* B9

In the next extract, the consultant unwittingly acted in a paternalistic manner towards both the patient and the son. His motives were clearly good and accorded with the advice of Bayles, in 1978, that 'a patient should be frankly told about the financial and emotional burden being shouldered by his family or friends'.[147] However, by his actions, the doctor imposed his values on the patient (it was the patient's duty to die) and denied the son the chance to explore whether he could have coped with caring for his father by having unpaid leave or employing carers:

> *I said to a widower deliberately (not to have treatment), he was...living...with an unmarried son who was forty or so...I think the son would have actually taken 6 months off to look after his father and probably lost his job had we tried to do something to prolong his life. Since he had a very good job I think that could have been affecting his own health in the future.* A26

However, it is not possible for all relatives to fully appreciate what it will mean to have a severely handicapped child or parent. The quality of the patient's life and the burden s/he represented to their family were linked but it appeared that the consultants felt it more appropriate to base recommendations on the quality of life of the patient (ie. the patient's best interests) than associated problems for the carers. This possibly represents a shift in position from earlier findings which conclude that physicians 'often allow parents to consider the impact of a handicapped child on the family when making decisions concerning withholding treatment'.[148]

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[147]Bayles MD. 'Euthanasia and the Quality of Life'. In Bayles MD, High DM (Eds). *Medical Treatment of the Dying: Moral Issues* 1978 GK Hall & Co, Shenkman Publishers, Cambridge, Massachusetts pp128-184 at p147.

[148]Strong C. Defective infants and their impact on families: ethical and legal considerations. *Law, Medicine and Health Care* 1983,11,4:168-181 at p169.

Withdrawing treatment immediately is not always possible. Sometimes, a minimum period of time must elapse before it is possible to apply to the courts to withdraw feeding/treatment.[149] This can place a huge burden on the family in the meantime:

> *We had a student recently with a sub-arachnoid haemorrhage. He'd been in another hospital and when he was conscious, he was transferred to us. Then he had a second haemorrhage and a large clot on his frontal lobes. We had to decide whether to let him die or to treat his aneurism. We treated him and it left him vegetative. He was newly married and his wife was screaming at us to kill him. She's the one who's got no life. He's going to live for a long time. It's destroyed her, both the families. It was the wrong decision but we only know this in hindsight.* B7

Several consultants felt their role was often to prevent such situations arising:

> *My job is to make sure patients are treated in such a way that they don't end up vegetative.* B20

4.4.1.7 Burden on Healthcare Staff

Several consultants spoke of the burdens faced by staff. Most had had '*heart-sink*' patients whose quality of life was perceived to be minimal yet they lived when death would seem in their best interest. These sort of patients were perceived as leading to high stress levels in areas such as intensive care and could lead to '*burn-out*' in staff.[150]

One consultant described how he would prefer certain patients to die during surgery:

> *Patients with severe aortic stenosis...very unpleasant terminal illness...all the time in your mind is 'I'd rather the surgeons operated and the patient died on the table than I have to sit and watch this patient die'.* A33

It was also felt that patients and relatives were much more willing to complain or to take legal action which added to the burden on staff and this could mean that treatment was continued inappropriately at times:

> *The complaints, they've gone up from 30-40 per year to 700 per year and there's a whole team of people now particularly employed to answer complaints, a lot of which are nothing short of malicious. So nurses and doctors are much more aware of avoiding litigation at all costs. In the end, that leads to bad treatment.* A14

4.4.1.8 Financial Costs

Financial considerations seemed to have less influence over the withdrawal of treatment than the withholding

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[149]In the case of someone who has been left severely brain-damaged, it is required, by medical opinion, and approved by the courts, to wait a minimum period of time before making the diagnosis of persistent vegetative state: *Practice Note (persistent vegetative state)*. [1996] 2 FLR 375.

[150]A finding supported by others: Calman KC. 'Ethical Implications of Terminal Care'. In: Freeman MDA. *Medicine, Ethics and the Law*. 1988 Stevens & Sons, London pp103-119 at p114.

of treatment. If a purchaser had agreed to fund a particular treatment it was up to the provider to decide how to allocate them to individual patients. So there seemed to be no evidence that anyone was being told that a patient was costing too much and treatment should be discontinued.

> *Although I've had my concerns about the way the health service has been run over the last few years so far I don't think I can remember a single incident where I've been forced to do something that I didn't want to do because of a managerial decision, certainly in terms of withdrawal of treatment.* A15

> *On an individual patient basis, where treatment has been established, money isn't an issue.* B11

> *We've had a set of four babies here and probably...in their first year they cost close to £700,000. That's a lot of money. Are we really prepared to do that when we're squabbling about the care of the elderly?* A13

Some consultants felt it was appropriate for them to think about the other demands on the NHS budget when making decisions, others did not:

> *The difficulty is with things like long term ventilation is that it costs a lot of money and you know ...spending £1000 a day or whatever on a child is £1000 that doesn't go somewhere else but obviously my responsibility is to that family not to the NHS budget so I think the issue of withdrawal of care is about resources but it's very difficult to make out quite how to apportion resources.* B8

> *You're almost training in rationing in a subliminal way from the time you're a medical student because you continually question the value of doing things, which is perfectly right. But also in the NHS you accept features which in other healthcare systems would be considered unacceptable...A lot of the decisions we make about the use of our resources...to a certain extent are driven by financial considerations as well as the patients' best interests.* C6

> *It's a hell of a lot cheaper if they (vegetative patients) die. Part of my management of acutely ill patients is to avoid the outcome of PVS.* B15

4.4.2 Criteria usually identified as inappropriate were...

4.4.2.1 Legal sanctions

Fear of civil or criminal sanctions was felt to be an inappropriate way to make decisions about withdrawing treatment but sometimes might prevail. Many of the consultants were acutely aware that there is a growing tendency for patients to complain or resort to legal action if things did not turn out as expected. There was criticism expressed of the doctors who practised 'protective medicine' and none admitted doing so themselves.

> *We do not practice medicine which is defensive in terms of medico-legal but one has to be aware of the medico-legal implications of what you are doing. You're selling a particular piece of goods which*

is advice and treatment. It's your obligation to ensure that that piece of advice is good. It's no use selling a Rolls Royce to a farmer who lives up a mountain track if what he really wants is a four-wheel drive. C11

Two doctors reported being in difficult legal situations:

We had one patient, she'd had a drug overdose and she was in ITU and we were talking of withdrawing ventilation and letting her die. Then there was a suggestion that she didn't take the overdose herself and the police were involved and we didn't know if we could turn off the ventilator or not. But then it turned out it was a malicious phone call to the police. A6

I have very many legal documents on this saying I would be required to treat this patient[151]*...and I have tried to point out in the most tactful terms to the legal people...that it is all very well them saying that but I don't know how I can practically do it without sedating this individual for 24 hours a day.* A34

4.4.2.2 Patient merit

Merit of the patient was deemed irrelevant by those who mentioned it:

People aren't treated on merit. Whether they are good, bad or indifferent as people, they all have the same problem and they are all offered the same treatment. C13

However, phrases such as '*a lovely lady*' were used in describing some patients or relatives which indicated doctor preference:

The foster mum was devoted and besotted and mentally deranged...she was very happy that we resuscitated him. A13[152]

Some consultants could be judgmental about their patients and one described two contrasting patients:

We had a difficult situation where we had a patient - she was grossly overweight and hadn't been out the house for two years. She had chronic emphysema and just lay on the sofa all day smoking and watching the telly. We had to decide whether to put her back on ventilation. She'd already been ventilated and then gone home...Maybe she would have gone on for a couple of years in the nursing home. She would have gone back to her chair smoking more fags and further damaging her lungs, you think why are we using our resources for this. D6

He's got motor neurone disease and he's very intelligent, a solicitor locally who still practices when he is well enough, a very nice chap, and we had to talk with him about whether to ventilate him or not and we decided we'd give it a go. D6

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[151]A seventeen year old boy in the care of the local authority who did not want to continue with dialysis.
[152]The consultant had just described how he had not been 'over-vigorous' in his attempts to resuscitate.

Doctors, like others, may be unaware that they are reacting judgmentally or in a biased way towards a patient and favouring a 'just deserts' approach. Since the doctor-patient relationship is essentially a private one based on trust, the lack of respect for the patient shown in this example is extremely disquieting. However, patients themselves may fail to respect those who are trying to help them by acting in an unacceptable manner.[153]

4.4.2.3 Rationing

Restrictions as to treatment options due to when in the financial year the patient presented for treatment were felt to be unethical:

> *The rationing of care because this particular area has used its quota of that particular treatment I find completely unacceptable.* C14

> *Cost should not be the sole criterion but it may have to influence the decision as there are limited resources in the country and it is not fair to gamble very large sums of money when there is very limited chance of success.* D1

Once treatment had begun, the question of withdrawing it because of financial cost did not seem to arise. However, where a particular treatment had been unsuccessful, and an alternative was possible, the way the consultants answered the interview questions seemed to indicate that the second treatment was considered as something new rather than a continuation of the initial decision to treat the patient's disease or illness. If the first line of treatment had not worked, any subsequent treatment was more of a 'gamble' regarding likelihood of its being successful. Therefore, the question would be framed in terms of withholding the subsequent treatment regime rather than withdrawing treatment. Whether this reflects a traditional way of viewing patient treatment or whether this is an artefact introduced as a result of the changes in the way healthcare has been 'purchased' since the 1991 reforms is beyond the scope of this thesis.

4.4.3 The parties involved in the decision

Again, these included the patient, the relatives, the healthcare team and the consultant with different views expressed as to how the decision should be made and by whom.

4.4.3.1 The patient

Sometimes patients would indicate that they wished to stop treatment but it was possible that this was not a true reflection of their wishes.

> *We have had a patient who...was saying she wanted to withdraw, she had a lengthy condition which was progressive but when you actually went to speak to her about it, it became clear that she wanted to stop because she felt she was a nuisance and a burden to everyone and you can understand that*

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[153]One case that was related to me concerned a patient requiring regular dialysis. He was frequently abusive and threatening to the nurses who had to carry out his treatment and often exhibited 'inappropriate' behaviour whilst undergoing dialysis. The help of the psychiatric team had been sought but his behaviour remained unchanged despite threats to discontinue treatment. Withdrawing treatment could have represented the adoption of a 'just deserts' model of healthcare but the patient's lack of merit was held not to be sufficient reason to refuse him further treatment.

there can be pressure to stop treatment on a busy ward and having stopped treatment we re-introduced it and I said I sense you are not ready to stop so we can restart and when you are ready to stop again we can stop. I don't think you should be frightened of doing these things. A2

A few consultants obviously did not feel that the patient could participate as an equal partner in the decision-making process. The patient's perception of his/her own abilities or future quality of life could be seen as distorted:

The elderly have unrealistic expectations of their health and abilities, that's quite a common problem. A14

Whether the consultant's role in such situations is one of educating the patient or side-lining the patient was not asked. However, it is submitted that respect for persons and patient autonomy demands that the patient is treated as an equal partner with effort made to enhance this.

4.4.3.2 The relatives

The input of relatives was important for educating the decision-making process:

When you see a patient in hospital and they are sick they may be quite different from the way they are at home and the relations and the GP have a lot to offer there...if the patient has been miserable and poorly and generally awful for the last year, it is different from if they have only been like that since they came into hospital. D7

It was recognised that blind reliance on what the relatives told the doctor about the patient and his/her wishes was inappropriate:

Families, of course, have a vested interest in some patients not surviving. It's difficult when that happens. B1

I personally try to avoid letting the family make decisions because there is a risk that they will say we don't actually want to look after disabled granddad, thank you very much. We've had enough of granddad. A19

Relatives can have their own agendas, they can use the patient's illness as a means of controlling the patient. A28

Most of the consultants felt it appropriate to involve the family if the decision to withdraw would lead to the death of the patient. They seemed to believe it was more difficult for relatives to agree to treatment withdrawal the younger the patient was:

In cancer treatment we try to involve the relatives at all stages and try and keep everyone equally involved...There comes a point, in any patient's treatment, where it's no longer sensible to carry on treating them actively and that decision has to be made. It is quite difficult for the patient to

understand. C6

I don't turn off ventilators without the parents' full agreement. A12

One (patient) who took an overdose...She was making good progress and then on the second or third night had a sudden arrest. Although she was resuscitated she went into a vegetative state and lingered for a very, very long time. It took a long time for her family to come to terms with the fact that she wasn't going to improve but the decisions were: when to stop ventilating and how long to keep on feeding and whether there was a chance that she'd improve. B3

Conflict between relatives was possible even though they have no legal status beyond advising the doctors as to the values of the patient and despite the fact that treatment decisions should be made in the 'best interests' of an incompetent patient:

I am currently involved in a case here where, I was looking after a patient over the weekend for a colleague and I was told that care was being withdrawn on the Friday...It became clear on the Saturday that the sons were extremely unhappy by the father's decision and it hadn't been sorted out and we re-introduced dialysis. I don't think anyone should ever be frightened of withdrawing treatment and reintroducing it. A2

Someone we put on a ventilator for a while. He had cerebral palsy and terrible respiratory problems which were getting worse. He was only 19 and his lungs were not functioning. We put him on a ventilator and kept him breathing and eventually, we had to look at his treatment. His parents didn't want him turned off and tried to investigate if there was anything that could be done. The decision still has to be made at some time and it was time. D6

Consultants related various strategies to overcome family objections. All said they continue treatment in the interim:

I would probably come to a compromise with the family if they wanted to treat the patient and I felt it was inappropriate. All I do is say, look we'll start and see what happens. But I think we should review this in a couple of days or whatever and then reassess it. I do that because sometimes my perceptions are wrong. I involve them in the decision-making process and continual involvement so that if what they want turns out to be incorrect they can actually see that as time goes on. B1

If we're going to change to a sort of withdrawal pattern...if there are major objections to that, we try to put down some sort of markers so that when one's reached it is clear to everyone that we've decided that this is a reasonable marker and...that's reasonable grounds for withdrawal. A17

Several described a 'collegiate' approach which meant that, whilst the second opinion would be presented as impartial advice to the family, was corroboration of the first consultant's opinion:

If the parents have religious beliefs then I will involve a minister or involve the hospital chaplain. I would always have a consultant colleague involved. There are two benefits. One, different

specialists see it from a different viewpoint and two, they get a different person with different views which balances out what you are telling them. I have to say I would select that colleague carefully. C9

4.4.3.3 The healthcare team

Several consultants indicated that the decision-making process involved their whole team and felt reassured by having others supporting their decision:

So we have to accept the responsibility of decision making and that responsibility works along the lines of, as a consultant you get to a point where you are unsatisfied with the clinical situation and then within the team, which includes your junior doctors, your nurses and the therapists, you will toss a few ideas in and see how they bounce, where the limits of care are going to be. If that supports your notional idea that you have got to a situation where there is no hope you then have a discussion with the family and friends by which time you will have ascertained their advocacy status whether they were close, whether they were remote, whether they have vested interests, all these factors are real, and you will have a fairly pragmatic discussion and if the people you are dealing with appear legitimate in their concerns, and you can do no more than get a feel for their legitimacy, and they agree that on their knowledge of the person concerned that they would not want their life sustained at any cost, then you can make very reasonable decisions. Whether they are ultimately legally acceptable decisions is a matter that I would prefer not to consider too deeply. D9

The next morning I went in and said I think it is time to consider withdrawing therapy and someone said, 'yes, you're right'. I'd got an ally and I felt so much better about it. A31

Working as a team could raise problems with conflicting views as to the appropriateness of continuing treatment or even whether treatment should have been started initially.

It's usually the primary providers that take the decision. They will do the operation, they will start the treatment, and when it gets to a certain stage they will then ask for my input about appropriateness of maintaining treatment and then withdraw the treatment. A6

It's sometimes very difficult for the members of the healthcare team to face facts when you can't actually treat a patient...if you're a clinician that talks about what you are doing and why you are doing it rather than making bad decisions with no consultation then you are going to get different reactions. B6

The concept of 'teamworking' was presented as the prevalent model but the patient was not always considered an equal member of the team which raises the issue of patient autonomy and respect for their views. Several consultants had expressed concern about legal sanctions if the decision was disagreed with and the team approach was obviously seen as a 'flakjacket'. It must be recognised that teams may be ineffective decision-makers due to the dominance of one or more members or over-deference to the opinions of one person by the rest. There is great scope for a consultant to speak the language of team-decision-making but in reality, be the sole decision-maker.

4.4.3.4 The consultant as prime decision-maker:

Several consultants felt that the decision to withdraw treatment, like that of initiating treatment, was theirs alone. Whether this was seen as a right, a privilege or a burden imposed by patients who refused to participate in the process varied.

> *The relatives should have enough trust in the doctors acting on their behalf, but that trust has to be earned. As it is, that trust is being destroyed, so the political scenario and the media as it is...and I'm not sure whether people totally trust their doctor as they used to.* D13

> *Some of them will just say 'do whatever you think is best'.* C10

This approach isolates the patient whose life may be at stake. The only person who knows whether their life is tolerable or worth saving is the patient. Trust has been lost because it has been abused by doctors acting paternalistically without reference to the patient (ie. because it is the 'right' of the doctor to make the decision). If the (competent) patient considers it too burdensome to be involved in difficult decisions, like whether to be resuscitated or not, s/he could be seen as investing the doctor with the power to act as a proxy decision-maker - a concept not yet acknowledged by the English legislature or judiciary - which can place the doctor under a burden which many prefer to share with the rest of the healthcare team. If it is a 'privilege' for the consultant to make the decision, it is one that must be made in good faith, in the best interests of the patient.

A few of the interviews revealed disparity between what the consultant replied when asked who should be involved in the decision to treat a patient and what seemed to be done in practice. One example follows from consultant A12:

> *It has to be the parents' decision.*
> *As far as the parents are concerned, I've had occasions when they have wanted to stop and I felt it was viable to continue.*
> *If we have a baby that we think shouldn't survive then the team should discuss it.*

4.5 Discussion

It can be seen that there is no clear consensus over withdrawing treatment. Therefore, when decisions are legally challenged, there is not always agreement amongst the medical experts. The starting point for doctors seems to be to ask what clinical gains (benefits) will the patient receive from this medical intervention? It is clear that different doctors construe benefit differently reflecting their own value-systems. Some could be very dismissive of different lifestyles.[154] Some doctors are prepared to take a holistic approach to health and recognise that it goes beyond physiological measurements. To them, the emotional and psychological well-being of the patient and his/her family is an important part of the healthcare relationship. It was also evident that treatment could be withdrawn, although clinically effective, because the toll was too high on the family.

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[154]For instance, one consultant would consider attendance at a wedding a life goal which it was appropriate for him to assist the patient in achieving. Another considered sitting on the sofa watching television an unworthy life compared with that of the solicitor who worked whenever able.

As McHaffie and Fowlie have likewise recognised, 'other concerns inevitably enter the equation: considerations of family stability; the impact of impairment and subsequent disability; emotional, social and financial costs'.[155] Evidence of all these was present in the interview responses. Campbell and McHaffie suggest that as patient's interests become 'inextricably interwoven with the interests of the family' it is a 'major part' of the doctor's exercise of 'clinical wisdom' to responsibly weigh these interests and resolve conflicts.[156] This analysis fails to question whether these 'conflicts' are best resolved by making paramount medical opinion. Admittedly, some relatives may have an unrealistic view of the long-term prognosis but so might some doctors.

The BMA states that treatment decisions should not be made on cost grounds since this would be unethical.[157] Yet NHS doctors are subject to government and purchaser restrictions so costs seemed relevant to many of the consultants although this could be seen as placing them 'on the slippery slope of compromised ethics'.[158] Some more readily accept this than others. There is a tension between the doctor's duty to an individual patient and to society. Newdick notes that Hippocratic Oath doctors pledged to 'follow that system of regimen which...I consider to be for the benefit of my patients' and the Declaration of Geneva says 'the health of my patient shall be my first consideration'.[159] Some of those interviewed seem to believe that their 'ethical duty goes beyond the individual patient to all other patients and to society as a whole'.[160] Similarly, doctors are told by the GMC that they should always 'seek to give priority...in the basis of clinical need' but at the same time must recognise the 'effects their decisions may have on the resources and choices available to others'.[161] Identifying 'need' is not always a science. Psychological need may often be greater than physical need so withdrawing treatment may be appropriate on clinical grounds but not necessarily psychological. Is the patient to be labelled a time-wasting hypochondriac greedily depleting time and resources belonging to others or should s/he be recognised as a patient whose real needs are not being met?

The effectiveness of treatment seems the primary consideration amongst the consultants interviewed. Then, quality of life which, regardless of the competence of the patient, would be balanced in the doctor's mind against the predicted benefits and burdens of treatment. The physician's assessment of quality of life may differ greatly from the patient's.[162] Some consultants recognise this and will continue treatment to help the patient achieve some personal goal. Kearsley argues that the 'appropriateness' and usefulness in terms of goals 'such as comfort, survival prolongation, convenience, cost and various other personal, professional and societal values' should be scrutinised.[163] It can be questioned, 'whose convenience?' - patient's, doctor's or society's? The burdens on patients and family/professional carers all seemed to be relevant factors but the burden on society seems of much lesser importance to the interviewees.[164] It was unclear whether the criteria were, or should be, of equal weight .

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[155]McHaffie & Fowlie, op cit n6 at p47. A similar conclusion is reached by Sklansky in Sklansky M. Neonatal euthanasia: moral considerations and criminal liability. *J.Med.Ethics* 2001;**27**:5-11 at p8.

[156]Campbell AGM, McHaffie HE. Prolonging life and allowing death: infants. *J.Med.Ethics* 1995;**21**:339-344 at p341.

[157]BMA. *Medical Ethics Today: Its practice and philosophy.* 1993 BMJ Publishing Group, London at p303.

[158]Loewy EL. Letter: Cost should not be a factor in medical care. *NEJM* 1980;**302**:697.

[159]Newdick C. *Who should we treat? Law, patients and resources in the NHS.* 1995 Oxford University Press, Oxford at pp276-277.

[160]BMA, op cit n157 at p308.

[161]Ibid.

[162]See, for instance: Sugarbaker PH et al. Quality of life assessment of patients in extremity sarcoma trials. *Surgery* 1982; **91**:17-23 (extremity sarcoma is a type of cancer of the bone generally found in the leg).

[163]Kearsley JH. 'Compromising Between Quantity and Quality of Life'. In: Stoll BA (Ed) *Ethical Dilemmas in Cancer Care*. 1989 The Macmillan Press Ltd, Basingstoke pp39-49 at p40.

[164]There is little written that acknowledges the validity of considering the burden on the family when making decisions to withdraw treatment. Hardwig cites a few examples and concludes the paucity of discussion of this point in relation to older children and adults whilst it is more openly discussed with regard to neonates, suggests that 'we may not really consider newborns to be fully fledged persons'. Hardwig J. The Problem of Proxies with Interests of Their Own. *J.Clinical Ethics* 1993;**4**:20-27 at p23.

Sometimes, the consultants indicated that they would be slower to withdraw treatment than the patient or family wished. Lee recognises that delays may occur after the family has requested treatment withdrawal before the 'physicians could accept that further care would not benefit the patient'.[165] Lee suggests it is 'possible that care withdrawal occurred only when patient or surrogate wishes coincided with physician attitudes, not out of respect for a patient's right to self-determination'.[166] Others have similarly found that '(p)arental input dominated their (the physicians') therapeutic choices, especially when parents wanted additional therapies'.[167] Rubenstein suggests that the reason for such behaviour could be to support parental autonomy and because of medicolegal concerns.[168] Likewise, two consultants had faced legal problems over treatment withdrawal and several revealed anxieties over possible litigation. Defensive medicine was condemned by all who mentioned it.[169] No one admitted to making decisions under threat of litigation but several mentioned that the threat was real. The willingness to continue treatment, even when clinically futile, was presented as patient/family-centred but a hidden reason could be to avoid conflict.[170]

Problems over treatment withdrawal can occur because physicians are taught 'how to deal with disease, but not how to deal with dying' and because 'they lack basic communication skills in areas fraught with intense personal tragedy'.[171] Carmel suggests that, despite evidence to the contrary, 'physicians tend to believe that elderly people prefer to delegate medical decision-making authority to their doctors'.[172] However, this was not obvious from the interview responses although some consultants showed more willingness to talk with patients than others. In another article, Carmel recognises that there is significant variation in practice about discussing death and life sustaining technology 'among different physicians and in the different Western societies'.[173] Some specialties were more likely to have consultants who were '*happy to natter with anyone about anything*' and who felt comfortable discussing end-of-life issues with their patients than others.[174]

4.6 Conclusion

It was clear that consultants selected from a variety of criteria in order to decide whether to withdraw treatment.[175] This is traditionally justified under the umbrella of clinical freedom and experience. However,

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[165]Lee DKP et al. Withdrawing Care: Experience in a Medical Intensive Care Unit. *JAMA* 1994;**271,**17:1358-1361.
[166]Ibid, at pp1360-1361.
[167]Rubenstein JS et al. Pediatric Resident Attitudes About Technologic Support of Vegetative Patients and the Effects of Parental Input - A Longitudinal Study. *Pediatrics* 1994;**94,**1:8-12.
[168]Ibid, at p11-12.
[169]Rees and Rees define defensive medicine as a term referring to 'clinical decisions motivated primarily not by what is believed to be the best for the patient, but by a desire to avoid litigation if the outcome should prove to be unsatisfactory'. Rees GJG, Rees AAD. 'Defensive Medicine or Malpractice Suits?' In Stoll BA (Ed) *Ethical Dilemmas in Cancer Care*. 1989 The Macmillan Press Ltd, Basingstoke pp51-62 at p52.
[170]This accords with the findings of Tilden et al. Tilden LP. Decisions about Life-Sustaining Treatment: Impact of physicians' behaviours on the family. *Arch. Intern. Medicine* 1995;**155:**633-9.
[171]Carmel S. Medical Students Attitudes Regarding the Use of Life-Sustaining Treatments for Themselves and for Elderly Persons. *Soc.Sci.Med.* 1998;**46,**4-5:467-474 at p468.
[172]Ibid.
[173]Carmel S. Wishes regarding the use of life-sustaining treatments among elderly persons in Israel: an explanatory model. *Soc.Sci.Med.* 1997;**45,**11:1715-1727 at p1716.
[174]This is not surprising. A doctor who finds it difficult talking with patients about difficult issues such as whether to resuscitate or not will possibly have opted for a specialty in which s/he feels more comfortable early on which requires less input of this nature. Thus, geriontologists believe in the intrinsic worth of their elderly patients and have probably have developed the skills to communicate with them. In contrast, the orthopaedic surgeons seemed to be less comfortable in discussing non-surgical issues with patients and seemed to show less understanding of ethical issues. However, this may be an artefact due to the small number of consultants surveyed.
[175]Others have suggested that the number of criteria is fewer than I have identified. For instance, Lo and Jonsen identified four criteria only: cost of treatment, patient wishes, quality of life and futility of treatment: Lo B, Jonsen AR. Clinical decisions to limit treatment. *Annals Int.Med.* 1980;**93:**764-8. I would categorise 'futility of treatment' as clinical effectiveness. Saunders adds a fifth criterion, the age of the patient to Lo and Jonsen's: Saunders J. Medical futility: CPR in Lee R, Morgan D (Eds) *Death Rites: Law and ethics at the end of life*. 1994 Routledge. London pp72-90 at p78.

the variability of approach found suggests that, in reality, an intuitive decision is made then justified later by judicious selection of supporting reasoning. The desire to keep the medical prerogative and exclusivity of decision-making seen in some of the consultants does not mean that all decisions made this way are wrong, only that some may be.

Greater self-awareness amongst doctors as to their own limitations in decision-making processes seems necessary. Failing to recognise that a patient's perception of quality of life may differ from the doctor's perpetuates discrimination against the aged, ill and disabled.[176] Likewise, those who make decisions according to their beliefs about what would be appropriate for their own relatives[177] may be acting 'virtuously' but the artificiality of imagined relatedness to the patient is possibly the most objectionable form of substituted judgment. However, brutal impartiality harms patient-physician relationships. A principle-based approach may be preferable.[178] Therefore, where the patient's own values can be discovered, as a way of educating the decision-making process, they should be. To do otherwise is to ignore the principle of autonomy.

The way treatment withdrawal decisions are made varies considerably. There is more scope for value judgments than with decisions to withhold treatment which are heavily based upon clinical prognosis. Withdrawal decisions are primarily based upon clinical prognosis, but the opportunity for a relationship to develop between doctor, patient and possibly family allows other considerations to enter the decision-making process. Some of these are value-laden and lack consistency yet they may trump clinical. These other considerations could vary from helping the patient achieve a life-goal such as living till a family wedding or the clinician's own fear of litigation or censure from colleagues. Consequently, scarce resources may be denied those in need. Several consultants spoke of difficulties managing expectations particularly in the light of media-publicised advances in medicine.[179]

It is important to note the differences between the factors used when withdrawing treatment rather than withholding it. When withholding treatment the doctors felt it inappropriate for 'family wishes' to educate the decision save in a few, rare cases. When withdrawing treatment the wishes of the family are considered relevant by doctors and are used as justification for 'futile' treatment to continue. Similarly, the burden on the family seems more important in the case of withdrawing treatment, probably because it is more apparent. If a patient has had a sudden onset illness or accident, the family has not yet faced any burden beyond the distress of seeing a loved one afflicted.[180] It seems that judges may be wrong in concluding that there is no difference in withholding and withdrawing medical treatment.[181] Many doctors advocate that the decisions 'feel different'.[182] They don't just 'feel different', it seems that they are made differently. Dickenson suggests that

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[176]Branson describes an incident in which two eminent transplant surgeons were stunned to realise that their own practice of allocating organs to those patients who did not have other pathologies or disabilities was discriminatory and failed to recognise the full worth of the disabled as persons. See: Branson R. Virtues, Obligations and the Prophetic *Vision. Kennedy Inst.Ethics J.* 1996;**6,**4:361-370. It is interesting to note that it seems that it is 'easier' to withdraw treatment from a brain-damaged patient than from one with physical injuries. Whether the decisions in such cases reflect value judgements about the worth of individual lives or merely a pragmatic approach based on a realistic appraisal of the quality of support that can be offered outside the hospital is not possible for this thesis to examine.

[177]This was evident with withdrawing treatment as well as with withholding treatment but specific examples have not been cited in this chapter since it seemed unnecessarily repetitive.

[178]Branson R. Virtues, Obligations and the Prophetic Vision. *Kennedy Inst.Ethics J.* 1996;**6,**4:361-370 at p363.

[179]For instance, Paris et al describe the case of a five-year old boy with major injuries. Once it was clear that recovery was not possible, the parents' goal moved changed to one of keeping their son alive and threatened legal action if treatment was withdrawn. Managing expectations and agreeing realistic goals is a major challenge for any health care provider. Paris JJ. et al. Beyond autonomy - physicians refusal to use life-prolonging extra-corporeal membrane oxygenation. *NEJM* 1993;**329,**5:354-7.

[180]As one consultant mentioned, (reported earlier), his job was to treat patients in such a way that they did not end up in a persistent vegetative state. Thus his treatment was aimed at avoiding future, predictable burdens for the family and the hospital (or NHS).

[181]As will be discussed in Chapter Six.

[182]Shaw AB. Acts of commission, omission, and demission or pulling the plug. *J.Royal Soc.Med.* 195;**88**:18-19 at p18.

medical ethicists may be wrong to insist on a 'no-difference' principle.[183] It cannot be assumed that doctors treat withholding and withdrawing differently 'out of ignorance'[184] therefore, there she argues there can be 'a coherent pattern to their attitudes'[185] and we should not 'condemn practitioner opinion as misguided'.[186] The emotional burden decision-making places on doctors should not be underestimated.[187] As Gould et al point out, doctors may be 'uncomfortable with diagnostic uncertainty' or believe s/he has 'failed the dying patient'.[188] Social and organisational features of the particular hospital, unit or ward may also exacerbate family-physician conflict.[189] It seems probable that the longer a doctor-patient/family relationship lasts, the more likely it is that individual values come into play as opposed to professional ones. This difference between the way decisions to withdraw treatment as opposed to withholding treatment are made may explain why certain types of conflict arise. Any proposal to improve decision-making will need to recognise the difference between withholding and withdrawing treatment for those involved; the emotional nature of medical caring and the anxieties treatment-withdrawal decisions create. The next chapter examines some of the different decision-making models that currently exist.

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[183]Dickenson DL. Are medical ethicists out of touch? Practitioner attitudes in the US and UK towards decisions at the end of life. *J.Med.Ethics* 2000;**26**:254-260.
[184]Ibid, at p254.
[185]Ibid.
[186]Ibid, at p259.
[187]For an analysis of the emotional burden placed on healthcare workers, albeit primarily from a nursing viewpoint, see: Smith P. *The Emotional Labour of Nursing*. 1992 Macmillan, Basingstoke, in particular chapter 6 'Death and dying in hospital: the ultimate emotional labour' at pp96-111.
[188]Door Goold S et al. Conflicts Regarding Decisions to Limit Treatment. *JAMA* 2000;**283**,7:909-914 at p912.
[189]Ibid, at pp912-3.

CHAPTER FIVE

DECISION-MAKING MODELS

This chapter examines non-legal models for making decisions on the withholding or withdrawing of medical treatment. At least three 'levels' of decision making are identifiable.[1] The clinical level is closest to the patient. Furthest from the patient is government policy which establishes 'a framework of national priorities and targets for improvement'.[2] Juxtaposed is the purchaser/provider level[3] in which the tension between government policy and patient best interests is evident in judicial review challenges.[4] Decision-making models are generally proposed either by economists, doctors or ethicists so the analysis will be conducted using these divisions: politico-economic, medical and ethical. It is recognised that all models are underpinned by ethical values of one kind or another so there are elements of overlap. The next chapter will examine how the judiciary make decisions in individual cases.

5.1 Economic/Political Models

5.1.1 QALYs

The use of Quality Adjusted Life Years is attractive to healthcare purchasers who believe that decision-makers should act to maximise the number of QALYs produced by the NHS as the only measurable 'health benefit'.[5] However, used with individual patients it poses difficulties, not least the unavailability of accurate information available at the time of making the decision.[6] The QALY approach requires deciding what quality of life the individual currently has, what it would be if treatment is given and life expectancy.[7] By including costs, comparison between patients and treatments can be made.[8] The increased emphasis on evidence-based medicine and audit will address the information deficit to some extent. However, the individual patient may have individual (possibly genetic) traits which might mean the treatment was either more or less successful in terms of years gained than the average. QALY research tends to be based on individual treatments and conditions whereas 'real' patients often have multiple pathologies. Value-laden it carries potential for abuse.

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[1]Academy of Royal Medical Colleges. *Priority Setting in the NHS: a discussion document.* 1997 Academy of Royal Medical Colleges, London.
[2]Department of Health. *The NHS: A Service with Ambitions* November 1996.The Stationery Office, London p38. See also, Department of Health, *A First Class Service: Quality in the NHS* 1998 The Stationery Office, London p7, para 1.14.
[3]The internal market was abolished, as proposed in *A First Class Service* op cit n2, p6, para 1.9, on 1 July 1999.
[4]For instance, *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.
[5]Nord E. Towards Cost-Value Analysis in Health Care? *Health Care Analysis* 1999;7:167-175.
[6]This deficiency looks set to be rectified in part by the current emphasis on clinical audit.
[7]The concept of Quality Adjusted Life Years normally used is where a healthy life year counts as 1 QALY and poor health gives a value of less than 1. Some conditions might be rated worse than death so could score a minus score. Health gains are measured in terms of fractions of QALYs per year. For instance, resetting an arm which has mended badly after being broken could produce a gain in utility of 0.1 QALY per year of predicted life expectancy. In a 10 year old child, expected to live until 70 years old, the overall gain could be 7 QALYs, but if the child has brittle bone disease, the net gain might only be 0.05 QALYs if the bone is liable to break again in 6 months. If the patient is 80 years old, s/he has already exceeded the average lifespan so any calculation of overall utility is necessarily impaired. S/he might come from a family whose members have all lived to 100 years so the gain is potentially 2 QALYs. However, the impact of carrying out surgery on such a person at 80 years old might itself reduce the overall gain significantly but this information is unknowable because it has not been tested.
[8]If, for example, a heart transplant costs £100,000, for that money the quality of the patient's life might improve from a score of 0.3 to 0.8 and the patient would be estimated to live an additional ten years. To work out the cost per QALY, the improvement in quality of life should be multiplied by the estimated increase in life span (the first calculation). Then, the cost of the treatment should be divided by the figure gained by the first calculation. In the example given, the cost of one QALY for a heart transplant would be £20,000. However, a hip replacement might cost £5,000 and improve another patient's quality of life from perhaps 0.6 to 0.8, an improvement of 0.2. If this patient is estimated to live for another 20 years, the cost of per QALY for hip replacement is £1,250. Therefore, to maximise the amount of health gain in the population for every pound spent, it makes more sense to abandon heart transplants and do hip replacements for everyone who needs one.

The limitations on treatment it produces are unacceptable to advocates of a positive duty to do everything possible for each patient.[9] It acknowledges that 'costs' are health activities (or 'opportunities') denied to another.[10] Williams suggests doctors must consider other patients and believes QALYs produce justice in the allocation of health chances or risks.[11] He aims to 'separate "efficiency" from "equity" with "efficiency" being kept free of interpersonal comparisons of welfare'.[12] This ignores the fact that healthcare is necessarily delivered in a personal manner. A humane system needs flexibility to enable 'magic' to happen particularly as 'health' is not just physiological. Withholding treatment just because 'opportunity costs' are too high fails to recognise that the NHS has an important humanistic role.[13] Medico-technological advances have raised public expectations. Consequently, the principle of justice seems offended when 'there are treatments which can prolong life but which are simply unaffordable'.[14]

Williams suggests there is consensus that the young should receive priority over the old.[15] Bowling agrees.[16] Williams rightly questions the validity of unequal treatment but fails to offer a convincing argument in favour of vertical equity. The alternative, horizontal equity, suggests that 'if one person is denied treatment in a particular set of circumstances, everybody must be denied treatment in those circumstances'.[17] This would be fairer than the current postcode 'lottery'.[18] Rigid equity leads to failure to take account of patient individuality and results in patients receiving insufficient treatment when capacity to benefit is considered.[19] Williams' answer is that patients unconsciously perform a QALY analysis when considering whether to have surgery. Also, he suggests, a weighting could be given incorporating vertical equity eg. setting a value upon treatment for the old less than that set for treatment given to the young removing the 'vague arm-waving of fine sounding rhetoric'.[20] Williams does not address the problem of what if society, or its elected government, decided that not only should the old be given a reduced value, but so should particular ethnic/cultural groups or anyone who has 'contributed' in some way to his/her illness.[21] He also fails to address whether, in order to reduce inequalities, certain groups should have enhanced opportunity to benefit.[22] Reducing people's lives to numbers denies their personhood. Focusing on health status, as the single measure of quality of life, fails to consider the individual's own assessment. Healthcare is patient-centred if delivered well. Representing medical decision-making as capable of mathematical solution merely obscures the difficult issues involved and perpetuates the myth that third party assessment of another's life is possible and valid. It is tantamount to applying a 'best interests' approach to competent people. Others suggest that, with the patient's cooperation, QALYs can be used to decide between two treatment options thus upholding patient autonomy.[23] It is hard to

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[9]One consultant interviewed reported that this is the approach taken by the Malaysian doctors whom she teaches regarding the care of the elderly particularly when 'peg' feeding is in question.

[10]Williams A. 'Economics, Society and Healthcare Ethics.' In: Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp829-842 at p830.

[11]Ibid.

[12]Ibid, at p832.

[13]Greaves D. Changing priorities in residential medical and social services. *J.Med.Ethics* 1997;**23:**77-81.

[14]Chantler C. In *Health Care: Resources, Choices and Decisions.* St Catherine's Conference Report No37 1993 The King George VI and Queen Elizabeth Foundation of St Catherine's, Windsor at p7.

[15]Williams A. 'Priorities - not needs'. In Corden A et al: *Meeting needs* 1992 Avebury, Aldershot at pp57-63.

[16]Bowling A. Healthcare rationing: the public's debate. *BMJ* 1996;**312**:670-4. See, in particular, p670.

[17]Williams, op cit n10 at p838.

[18]For instance, with regard to provision of in-vitro fertilisation treatment across the country.

[19]Williams concedes this point: Williams, op cit n10 at p839.

[20]Ibid, at p840.

[21]State oppression of different groups, as practised by the Nazi regime, still exists today worldwide. See also the concerns regarding treatment trials in Hutton JL, Ashcroft RE. Some Popular Versions of Uninformed Consent. *Health Care Analysis* 2000;**8:**41-52 at p50.

[22]For example, Asian women and refugee women who do not speak English well or who come from a male-dominated society find it difficult to access healthcare particularly regarding sensitive issues: Department of Health. *Saving Lives: Our Healthier Nation* July 1999 The Stationery Office, London para. 9.32, figure 9.8.

[23]Mason JK, McCall Smith RA. *Law and Medical Ethics* 5th Edn.1999 Butterworths, London at p303.

see how this can be achieved since knowledge (and power) is unevenly distributed in the doctor-patient relationship. Grimley Evans notes the impossibility of weighing one good against another which is what QALYs try to do.[24] QALYs discriminate against the elderly and ignore the '*proportional* loss or gain of quality of life'.[25] They are discriminatory and sustain an 'aristocracy of the fortunate' because those born healthy automatically score higher in QALYs. Respect for persons requires that the state is obliged to 'defend its citizens' with impartiality.[26]

Harris argues convincingly that medical resources should be concentrated on maximising the number of lives saved: 'it is lives that are valuable and not life-years'.[27] Yet, the present government has fallen into the trap of detailing the number of 'years of life' lost alongside the number of 'lives' it expects to 'save' with its reforms.[28] Harris thunders: 'the injunction "maximise QALYs"...encourages health-care providers to choose, not the treatments but the patients, who will generate the most QALYs.[29] This involves not only ageism and sexism, but also injustice, unfair discrimination and a positively Thatcherite preference for the fortunate.'[30] Ultimately, QALYs are 'insensitive to distributive fairness' issues.[31] Rawles likewise points out that '(h)ighest priority would be given to patients with disabling or distressing conditions compatible with a normal expectation of life that could be treated cheaply, preferably as outpatients'.[32]

The QALY model also fails to answer the question of how long to continue treatment once started. As Goulden says, 'some therapies such as maintenance haemodialysis or aggressive surgery for certain cancers are a very poor buy but would be almost impossible to discontinue'.[33] The QALY approach suggests that octogenarians with cancer receive low priority regarding surgical intervention until their condition deteriorated to such an extent that terminal care could be offered.[34] Therefore, logically, where death is inevitable, early termination of the patient's life should be a viable treatment option.[35] Public policy grounded on QALYs could 'undermine public confidence in and respect for government and health policy makers'.[36] Harris's prophesy became increasing true during the 1990's culminating in the election of a new government pledged to end the internal market.[37] However, QALYs have encouraged academic debate about resource allocation. Mooney's suggestion 'that doctors' opinions should not be the basis of health services policy', lacks credibility.[38] Having a healthcare policy shaped by politicians and paid financial managers denying input from clinicians actively involved in patient care means that individual patient needs are sacrificed upon the altar of efficiency resulting

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[24]Grimley Evans J. Rationing Health Care by Age: The Case Against. *BMJ* 1997;**314:**822-5. For example, hip replacements and cataract operations are not equivalent even if they were calculated to produce the same net QALY.

[25]Mason & McCall Smith, op cit n23. Their emphasis.

[26]Harris J. The case against: what the principal objective of the NHS should really be. *BMJ* 1997;**314:**669-672 at p672.

[27]Harris J. Unprincipled QALYs: a response to Cubbon. *J. Med. Ethics* 1991;**17**:185-188 at p185.

[28]Department of Health. *Saving Lives: Our Healthier Nation* July 1999 The Stationery Office, London.

[29]As Goulden has pointed out, when a patient's individual quality of life and life expectancy is calculated in QALYs and the various treatment options considered, it may mean that a dying patient may qualify for a kidney transplant but not for a heart transplant - an illogical distinction to make between two ultimately fatal conditions in the same patient. Goulden P. 'Non-treatment orders, including Do Not Resuscitate (DNR)'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp733-742 at p740.

[30]Harris J. Unprincipled QALYs: a response to Cubbon. *J. Med. Ethics* 1991;**17**:185-188 at p186.

[31]Anand P. QALYS and the Integration of Claims in Health-Care Rationing. *Health Care Analysis* 1999;**7:**239-253 at p 243.

[32]Rawles J. Castigating QALYs. *J.Med.Ethics* 1989;**15**:143-147 at p147.

[33]Goulden P. 'Non-treatment orders, including Do Not Resuscitate (DNR)'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichesterat pp733-742 at p740.

[34]Rawles, op cit n32 at p147.

[35]Rawles, op cit n32, particularly at pp144-6 where Rawles compares outcomes in terms of QALYs for a patient with severe arthritis of the hip; one receiving renal dialysis and an unconscious patient on ventilator support.

[36]Harris J. Unprincipled QALYs: a response to Cubbon. *J. Med. Ethics* 1991;**17**:185-188 at p187.

[37]Some of the interviews in connection with this thesis were conducted during the fortnight following the general election and contrasted markedly with ones conducted before. There was a palpable sense of excitement among the consultants. They all welcomed the change eagerly as something that would be positively beneficial for their patients.

[38]Mooney G. QALYs: are they enough? A health economist's perspective. *J.Med.Ethics* 1989;**15**:148-152 at p148.

in a model lacking compassion and condemned as barbaric by the society whose resources are being used. Mooney, despite his overall support of QALYs, accepts their failure to recognise that what counts as a benefit to the individual may not be included in the current concept of QALYs, a point missed by many other supporters.[39] Some health authorities have rejected utilitarianism in favour of humanitarianism although dispassionate application of QALY's would not have supported their decisions.[40]

An alternative to QALYs is suggested by Nord.[41] A SAVE is the unit given as the value of a young life saved from death and restored to full health.[42] Mason and McCall Smith point out that, like QALYs, it is ageist and reduces people to numbers.[43] Nord is sensitive to this issue and advises that ' numerical estimates of value should not replace critical thought and responsible discussion'[44]. Like QALYs, the individual clinician is left to assess the individual patient. Therefore, as a treatment decision-making model, it is equally subject to variation and many of the criticisms directed at QALYs also apply to SAVEs. It is difficult to see how either could inform individual decisions since either they will operate to produce a total ban on treatment[45] or the clinician would be faced with 'guestimating' the QALY/SAVE score or interrupting the consultation to carry out an actuarial calculation.[46]

Another variation is the 'fair innings model'.[47] Older patients do often receive less aggressive therapy than younger patients,[48] but that alone is not proof that age is decisive. Disease is often more advanced[49] and more difficult to cure in the elderly and there is greater likelihood of other health problems.[50] It would seem appropriate that age is a relevant factor when deciding to withhold or withdraw medical treatment but biological age may be more important than chronological age.[51] Campbell points out that 'there is no fairness about disease or death' and it is 'misleading to compare life to a game of cricket' by talking of people having had a 'fair innings'.[52] He holds that simply because some older people take this approach to their own healthcare, this is merely a 'voluntary relinquishing of health care opportunities' not 'a policy of mandatory preference for the young'.[53] Callahan, though, advocates that chronological age alone should be the determinant as to whether treatment is provided.[54] Hunt considers his approach discriminatory and disrespectful of individual autonomy as it is based upon a view that the elderly are regarded as 'the means to a greater social good, rather than as ends in their own right'.[55] Others suggest 'the rights of the younger child...seem straightforward. The younger child will be losing more of his/her life than the older and therefore loses more'.[56] But societal/genetic/environmental factors and fate all have a part to play so the calculation is

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[39]Ibid, at p152.
[40]See for instance: Anon. *Daily Telegraph* 19 July 1996: Doctors defend cost of allowing girl to die at home.
[41]Nord E. An alternative to QALYs: the saved young life equivalent (SAVE). *BMJ* 1992;**305**:875-877. He reports that a mathematical model to estimate the values for various outcomes of treatment is being constructed by the National Institute of Public Health in Oslo.
[42]Like the acronym NICE, the acronym SAVE seems named to appeal.
[43]Mason JK, McCall Smith RA. *Law and Medical Ethics* 4th Edn.1994 Butterworths, London at p262.
[44]Nord, op cit n41 at p876.
[45]Hence, a potentially unreasonable fetter on the Health Authority's decision-making powers: *R v North West Lancashire HA, ex parte A, D & G* [2000] WLR 977.
[46]All alternatives being equally non-conducive towards good clinician-patient relationships.
[47]Williams A. Rationing health care by age: the case for. *BMJ* 1997;**314:**820-2.
[48]Particularly in the field of oncology: Samet J et al. Choice of cancer therapy varies with age of patient. *J.A.M.A.* 1986;**225**(24):3385-90.
[49]Hunt RW:A critique of using age to ration health care. *J.Med.Ethics* 1993;**19**:19-23.
[50]The medical terminology is 'co-morbid conditions'.
[51]'Biological' age is the age the patient appears to be based on health/fitness assessment.
[52]Campbell A et al. *Medical Ethics* 2nd Edn. 1997 Oxford University Press, Oxford at pp139-140.
[53]Ibid.
[54]Callagan D. *Setting limits: medical goals in an aging society*. 1987 Simon & Schuster, New York.
[55]Hunt RW:A critique of using age to ration health care. *J.Med.Ethics* 1993;**19**:19-23 at p21.
[56]Lewis PA, Charny M. Which of two individuals do you treat when only their ages are different and you can't treat both? *J.Med.Ethics* 1989;**15**:28-31 at p30.

more complex than indicated. If age is to be considered, chronological age should take second place to biological age and evidence as to expected lifespan of the individual patient.[57] However, it is submitted that where there are limited resources available to a publicly-funded healthcare system it may be appropriate for society to consider whether the same level of treatment should be provided for an older person as for a younger person. It is also appropriate, and necessary, for the clinician to consider the patient as the 'sum of his/her parts' rather than simply a single condition which is how most QALYs are calculated.[58] Effective decision-making takes account of all relevant physiological factors. Age alone should never be decisive unless society has democratically decided it should be in some situations. Hunt agrees: '(e)ven if age is considered to be a typical medical indicator, it would be extraordinary to base a life and death decision upon any *one* medical indicator.[59]

Ultimately, apart from the withholding of treatment from the old, and identifying cost differences between similar treatments, these models do not indicate which treatments should be provided by the state and which left to individual responsibility.

5.1.2 Allocating responsibility between individual and state

The Netherlands' healthcare system[60] is a mixture of public and private funding. The state decides which services will be covered and it seems most private insurers follow this. It also has the right to limit high technology procedures to only a few hospitals. Certain conclusions have been made: ineffective procedures should be stopped; withholding potentially beneficial treatment from a person because of lack of money should only be done 'after effectiveness studies' have been carried out; personal factors such as sex, age, social value, and own responsibility for one's illness should 'never be taken into account'; the healthcare system should not fund non-healthcare procedures eg. infertility treatment and finally, personal responsibility for some types of healthcare should be encouraged eg. dental care. Funding long-term care for those who cannot care for themselves is prioritised.[61] The Dunning Report recommended that medical treatment is only provided if the patient's need has passed through the four layers of the sieve.[62] The questions asked are:

1 is it necessary care, from the community point of view?
2 is it demonstrated to be effective?
3 is it efficient?
4 can it be left to individual responsibility?

There is much to commend in its communitarian approach balancing individual and social responsibilities.[63] However, there is potential for discrimination. The community could decide treatment for certain groups is not necessary. These sieves fail to answer the problem of what to do when treatment is effective but inefficient.

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[57]It possibly then becomes a variation of the medical model of decision-making.
[58]Harris RA, Nease RF. The importance of patient preferences for comorbidities in cost-effectiveness analysis. *J.Health Economics* 1997;**16**:113-119.
[59]Hunt, op cit n55 at p22. His emphasis.
[60]Described in *Choices in Health Care*: Dunning AJ (Chair). *Report of the Government Committee on Choices in Health Care* 1992 The Ministry of Welfare and Cultural Affairs, Rijswijk, The Netherlands,.
[61]Borst-Eilers E. In *Health Care: Resources, Choices and Decisions*, op cit n14 at pp4-5.
[62]*Choices in Health Care*, op cit n60 at p24.
[63]I am joined in this conclusion by John Butler. Butler J. *The Ethics of Health Care Rationing: Principles and Practices.* 1999 Cassell, London at p91.

Utilitarianism trumps patient best interests in this model unless some way is incorporated to identify levels of inefficiency that will be tolerated in the interests of justice.

5.1.3 Efficiency-based models

The 1991 reforms aimed to control doctors by giving control over what types of treatments and drugs could be prescribed to health authority purchasers.[64] Whereas rationing prior to 1991 occurred more through demand exceeding the possibility of supply,[65] post-1991 the number of 'patient episodes' paid for by the DHA and the types of treatment were strictly limited. Britain now places strong emphasis upon healthcare provision being 'efficient'.[66] Healthcare policy in the 1990s modified the QALY model by linking costs of treatment with effectiveness of treatment thereby producing the 'cost-benefit' or 'cost-effectiveness' model. Essentially a utilitarian approach, some believe that greater efficiency can eliminate any need for rationing.[67] Randall suggests that not all elderly people want all the treatment they receive; some services could be taken out of the NHS remit; advances in disease prevention will reduce expenditure on treatment and the efficiency of providers will increase.[68] If the patient, from an informed stance, refuses treatment, the doctor should accept this - the money saved can be used elsewhere.[69] Achieving health targets could reduce demand[70] but often, as fast as one disease is conquered, another replaces it.[71] Better management reduces wastage.[72] The purchaser-provider split meant that instead of the hospitals going on end-of-year spending sprees, the health authorities do. 'Waiting list initiatives'[73] are simply end-of-year spending sprees although they sound laudable. Controlling healthcare expenditure by 'identifying separate pockets of money' for different procedures produces inefficiency.[74] Similarly, moving services from NHS to Local Authority responsibility does not increase the funds available - it only leads to conflict.[75] It is too early to establish whether the pooling of resources without 'ring-fencing' will achieve a 'seamless service'.[76]

Rationing decisions vary according to purchaser philosophy with patients receiving unequal access to often inefficient care. Some funded 'experimental' treatment, others did not.[77] As Dworkin recognises, whether the state should fund 'experimental' treatment is one of the most problematic issues in healthcare resource allocation.[78] The boundaries between 'effective' and 'experimental' need defining. Effectiveness only applies when treatments have been tried and their success rates and 'opportunity costs' measured. However,

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[64]Rivett G. *From Cradle to Grave: Fifty years of the NHS.* 1998 Kings Fund, London at p383.
[65]Termed 'rationing by deterrence or delay': Parker R. Social administration and scarcity. In Butterworth E, Holman R (Eds) *Social welfare in Modern Britain.* 1975 Fontana, London p204-212. Hospitals would run out of money before the year end so would close wards 'for decorating' or face penalties for over-spending.
[66]NHS Executive. *Priorities and Planning Guidance for the NHS:* 1997/8. June 1996 NHSE, Leeds.
[67]Randall A. In *Health Care: Resources, Choices and Decisions*, op cit n14 at p2.
[68]Randall, ibid.
[69]Randall, ibid.
[70]For instance, the targets set in *Health of the Nation* 1992 HMSO, London.
[71]For instance, the rise of new diseases such as AIDS and new variant Creutzfeld-Jacob Disease. Also, as people live longer new illnesses/diseases due to the aging process become more evident.
[72]For an example of poor management resulting in 'chaos' see: 'Failures in Admission Procedures' W.255/91-92. *Report of the Health Service Commissioner Select Investigations April - Sept 1992* HMSO, London at p3.
[73]For instance as discussed by Deborah Evans, Director of Purchasing for Avon HA. BBC Radio Bristol, *The 7am News* 30 January 1997.
[74]James J. In *Health Care: Resources, Choices and Decisions*, op cit n14 at p5.
[75]See, for example, *R v The Brent and Harrow Health Authority, ex parte The London Borough of Harrow* TLR 15 October 1996.
[76]Introduced in April 2000 - see Chapter 2.
[77]See, for example, *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.
[78]Dworkin R. *Sovereign Virtue: The Theory and Practice of Virtue.* 2000 Harvard University Press, London at p308.

'opportunity cost' requires judging 'the relative value of different options'.[79] Comparing different options for one condition and also comparing different conditions is highly problematic. 'Treatments...shown to be the most cost effective...may be favoured over treatments with greater efficacy'.[80] 'New measures of efficiency...which reflect and encourage more appropriate and effective healthcare' are required.[81] An efficiency-based service requires high quality data so the most effective treatments can be selected. This means conducting extensive (and expensive) research comparing existing treatments on a scale unknown in the U.K. Rationing is unpopular particularly when it appears arbitrary and unreasonable. It is easier to gain public approval when scientific justification is possible. Hence the promotion of clinical effectiveness. Even though this is not objectively determinable the decision appears so.[82] However efficiency models discriminate against certain groups[83] and can lack the humanity a healthcare system should possess.

Cost-benefit/cost-effectiveness is a 'good housekeeping' model applied to healthcare. Official approval is seen in the introduction of NICE.[84] Cost-benefit calculations take no account of personal costs to the patient such as slower recovery.[85] Clinicians are alert to these costs and prefer to have the freedom to prescribe the more expensive drug/treatment where appropriate. However, bias towards more expensive products as 'better' can be present in clinicians as well as patients.[86] Whilst doctors should have awareness of costs, health economists should not 'attempt to dictate the resolution of clinical problems in financial terms.'[87] Otherwise, it could be considered 'wrong to use resources to keep (severely handicapped neonates) alive that could be used to save or enhance the lives of others'.[88] There is also a danger, which seems inadequately recognised, that focusing on improving the health of the nation means giving lower priority to palliative healthcare than curative. Efficiency is defined in terms of achieving a 'cure' or improved health status which is the underlying theme of the present model of healthcare provision.[89] Palliative care achieves neither cure nor improvement. Focusing on providing a mixture of clinically effective and cost-effective healthcare for the population as a whole as well as for the individual means concentrating on the youngest in society at the expense of older members. The restoration to full health of a neonate, or the prevention of brain damage resulting from a poorly-managed delivery, is the best means of 'investing in the country's future'.[90]

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[79]Black D. Paying for health. *J.Med.Ethics* 1991; **17:**117-123.

[80]Coiera E. The Internet's challenge to healthcare provision. *BMJ* 1996; **312:**3-4.

[81]Dixon J, et al. Financial meltdown for the NHS? *BMJ* 1996; **312:**1432-3.

[82]For instance, in some cases the treatment can be objectively shown as effective - it produces a 'cure' eg. the bacteria are eliminated; but in others, the effectiveness of the treatment is measured in subjective terms such as the patient reports feeling 'better' - an unmeasurable quality. The difficulty of measuring 'success' is recognised in *A First Class Service* op cit n2, para 4.54.

[83]There can also be problems with regard to participation in research trials by certain ethnic minority groups. If they do not participate, the evidence needed to possibly tailor treatments and services to their particular needs may not be generated.

[84]See: *A First Class Service,* op cit n2, para 1.15: 'NICE will...assess new drugs, treatments and devices for their clinical and cost-effectiveness'.

[85]To demonstrate how cost-benefit works in practice, consider a patient with a bacterial infection. Antibiotic A might cost £20 for the course of treatment, net benefit being the patient is cured. Antibiotic B might cost £10 for a course of treatment, patient is cured. Therefore, to achieve the same benefit, using Antibiotic B makes more economic sense than Antibiotic A. However, Antibiotic B might take longer to cure the patient so the patient loses more time from work, or it might have additional side-effects. A calculation of cost-utility was carried out with regard to Donepezil (Arocet) by Wessex Institute for Health Research and Development See: *Report 69 Evidence based purchasing.* June 1997 NHS Directorate South and West, Bristol. The range was between £21,000 to £200,000 per QALY gained. Individual costs ranged from £2,000 to £10,000 over the expected course of treatment plus other probable associated expenditure. The benefit to the patient can be immeasurable. However, when a health authority is looking to gain the maximum health benefit from its limited funds it can be seen as an inefficient way to spend a lot of money - ultimately it is an ineffective treatment because it does not cure, it merely provides a window of normality lasting about six to twelve months.

[86]Clinical trials often now analyse the cost-benefit of new treatments. Unless the initial trials are 'blinded' not only as to which of the alternative therapies each patient is receiving but also cost, conclusions may be open to challenge: Freemantle N, Drummond M. Commentary: Should Clinical Trials with Concurrent Economic Analyses be Blinded? *JAMA* 1997;**277**:63-4.

[87]Mason & McCall Smith, op cit n43 at p262.

[88]Fairbairn G. Enforced death: enforced life. *J.Med.Ethics* 1991;**17**:144-9.

[89]The change of government has not produced any change in emphasis in this respect. Much weight is being placed on the development of primary care as seen in both the Health Act 1999 and the Department of Health's *Saving Lives: Our Healthier Nation* July 1999 The Stationery Office, London.

[90]Swartz K. Editorial: Babies are coming: Don't cap Medicaid. *JAMA* 1997;**277**:421.

Whilst some decisions are taken out of the hands of the clinicians, other decisions remain such as to which patients to prefer`. This avoids too open a challenge to medical autonomy.[91] Eddy argues that this 'push(es) the difficult choices about costs vs quality to individual decision makers'.[92] Without knowing the health/economic outcomes regarding different treatment options, it is impossible for the individual clinician to choose without personal (possibly unconscious) bias or with conviction. Little was done between 1991 and 1997 to determine the **effectiveness** of treatment or to recognise that '(e)ven where the effectiveness of a particular procedure is not in general judged to be high, it might be both effective and appropriate in certain circumstances for an individual patient'.[92A] Judgments focus on the relative worth of different treatments not on individual need. For each patient to receive the best treatment, regarding their particular pathology and circumstances, means allowing some clinical freedom. Separating healthcare provision from purchasing may have been a 'reaction to the excessive income, privilege and autonomy of physicians'[93] but expecting doctors to make individual patient treatment decisions by balancing costs against benefits without proper information is unrealistic.

It is now recognised that making short-term savings disregarding long-term outcomes is illogical.[94] Effectiveness continues to be linked to costs although the Blair government is less willing to make cost-effectiveness as visible as its predecessor. The 1999 reforms aim to control doctors through greater accountability and the introduction of national standards, guidelines and targets. Accountability requires visibility of process and persons. However, a tension can be seen between the way the government aims to make doctors more accountable and yet is trying to lessen its own accountability by using public consultation to spread responsibility.[95]

5.1.4 Public Involvement Models

The 'Oregon' model is perhaps best known. Most states limit eligibility for Medicaid to keep costs within budget. Oregon decided to widen access by prioritising certain pairs of conditions and treatments and funding the top 714[96]. One thousand residents were asked to rank condition-treatment pairs which had been based on patient benefit, duration of benefit and cost (a cost:utility approach). A final ranking with public 'ownership' of the list was produced.[97] Some treatments were still withheld but the process seemed fairer although only costs and benefits were considered not ethics.[98] However, the priorities set failed to secure political or professional acceptance and 'ran foul' of anti-discrimination legislation.[99]

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[91]Klein R, Day P & Redmayne S. *Managing Scarcity: Priority Setting and Rationing in the National Health Service.* 1996 Oxford University Press, Buckingham at p71.

[92]Eddy D.M. Connecting Value and Costs: Whom do we ask, and what do we ask them? *JAMA* 1990;**254:**1737-9.

[92A] Department of Health. *The NHS: A Service with* Ambitions 1996 The Stationery Office, London at p39.

[93]Marmor T. In *Health Care: Resources, Choices and Decisions,* op cit n14 at p10.

[94]Hence their emphasis upon researching into the most appropriate forms of treatment. One of NICE's projects is to evaluate which of the 600 different hip replacements joints is the most effective in terms of cost of joint, operating costs, durability and patient mobility: NICE *The effectiveness and cost effectiveness of different prostheses for primary total hip replacement.* 4 July 2000 The Stationery Office, London, www.nice.org.uk. Accessed 27 January 2001.

[95]It is interesting to note that following the debate about Child B, Cambridge and Huntingdon HA began local consultation about what treatments should be funded. However, despite the justificatory gloss which can now be put upon their decisions, when the parties involved in the consultation process are examined, it is obvious that there is a bias in the selection process which probably sways towards upholding the status quo and the process was probably little more than political gesturing. Personal communication.

[96]The funds ran out at this point.

[97]Some modification was carried out as initially provision of dental braces was ranked more highly than treatment for curable Hodgkin's lymphoma. Dixon J, Welch HG. Priority Setting: lessons from Oregon. *The Lancet* 1991;**337:**891-894.

[98]Relman AS. The trouble with rationing. *New Eng.J.Med.* 1990;**323:**911-913.

[99]Blumstein JF. The Oregon Experiment: The role of cost-benefit analysis in the allocation of Medicaid funds. *Social Science Medicine* 1997;**45**,4:545-554 at p551.

John Major's government rejected this approach stating '(n)o...list of treatments could ever hope to accommodate the range and complexity of the different cases which individual clinicians face'.[100] It believed 'there would be a real risk of taking decisions out of the hands of the clinicians treating patients' and making it the 'province of others who possess neither the experience of caring for patients nor the expertise to make such decisions'.[101] However, passing resource allocation to unelected purchasers[102] resulted in the Oregon model creeping into this country, with minimal guidance from the NHS Executive on priorities[103] and variable amounts of public input.[104] It looks an increasingly important model following the introduction of Primary Care Groups and the National Survey of Patient and User Experience.[105]

Public input was sought by the New Zealand government to help identify the 'core services' of the public healthcare system.[106] Seven representative groups[107] were asked what are the benefits of treatment, is it value for money, is it fair and is it consistent with the community's values and priorities?[108] The different groups seemed to agree that the 'criterion of need' is favoured as the moral basis for distributing healthcare.[109] However, 'need' is a very subjective concept and incapable of being defined objectively. The rejection of waiting lists and regional inequity earned it widespread approval.[110] Although the workshops satisfied a moral principle regarding public involvement in decisions directly impinging upon their lives they have not resolved the hard questions of how to allocate limited resources. The eventual conclusion was that the core services comprised all that were currently being provided in that 'there is no obvious or right set...whatever set is decided upon will be contentious'.[111] Since then, the New Zealand government has continued to work on developing decision-making processes that are 'fair in the way conclusions are reached...guided by acceptable principles and...based on reasoning that is defensible'.[112] Consultation has continued, practice guidelines have been developed and 'a way to reduce hospital waiting lists in a manner that is fair and transparent' have been achieved with 'a high level of acceptance of the strategy' by professional groups.[113]

In France, the government interfered little with healthcare and priorities for treatment until recently. A right to health is guaranteed to all French citizens and residents.[114] Any priorities that exist seem to come from cultural preference rather than logic and audit.[115] However, as in Britain, patients want more say and

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[100]*The NHS:A Service with Ambitions*, op cit n2 at p39.
[101]Ibid.
[102]Dixon J, Welch HG. Priority Setting: lessons from Oregon *The Lancet* 1991;**337:**891-894.
[103]*The NHS:A Service with Ambitions,* op cit n2 at p39.
[104]Ham D. Priority Setting in the NHS: reports from six districts. *BMJ* 1993;**307**:435-8.
[105]*A First Class Service*, op cit n2 para 4.59. The first nationwide survey of 150,000 NHS patients and users' views was announced in 1998: Department of Health. DOH 98/333, 12 August 1998 The Stationery Office, London. See also: Bowling A. Health care rationing: the public's debate. *BMJ* 1996;**312:**670-4.
[106]Campbell AV. *Ethics Workshops: Public participation in discussing ethical issues in defining core services. A report to the National Advisory Committee on Core Health and Disability Support Services* March 1994 NACCHDSS, Wellington, New Zealand.
[107]A series of seven workshops was held to obtain input from different perspectives: elderly, disabled, rural, urban - low income, Maori, Pacific Islands and youth.
[108]Campbell AV. *Ethics Workshops,* op cit n106 at p 3.
[109]Ibid, at p 11.
[110]Butler J. *The Ethics of Health Care Rationing: Principles and Practices.* 1999 Cassell, London at p103.
[111]Campbell AV, Gillett G. *Ethical issues in defining core services. Discussion papers prepared for the National Advisory Committee on Core Health and Disability Support Services.* 1993 NACCHDSS, Wellington, New Zealand at p74.
[112]National Advisory Committee on Health and Disability. *Sixth Annual Report to the Minister of Health.* 'Doing the Right Things Right: Allocating Resources using Processes most of us can Support'. 1996 National Advisory Committee on Health and Disability, Wellington, New Zealand www.nhc.govt.nz/pub/annual6/right.htm accessed 26 January 2001.
[113]National Advisory Committee on Health and Disability. *Eighth Annual Report to the Minister of Health.* 1999 National Advisory Committee on Health and Disability, Wellington, New Zealand at p4.
[114]Geschwind HJ. Health Care in France: Recent Developments. *Health Care Analysis* 1999;**7:**355-362,357.
[115]According to Georges Arbuz this is because of the French love for children: In *Health Care: Resources, Choices and Decisions,* op cit n14 at p5.

healthcare costs are rising.[116] The government, despite resistance from doctors, is moving healthcare into the national and social arena. The Social Security focus is on 'solidarity, justice and human dignity for all'.[117] In 1992, a Central Committee of Public Health, with members from various spheres, was given the job of defining healthcare priorities, educating the public and encouraging preventative medicine. [118] To avoid discrimination, the elderly have a charter of rights and freedom.[119]

Public participation is the politician's 'flakjacket' - if the decision is politically sensitive or requires a high degree of specialist knowledge, gaining public 'ownership' keeps voters happy. Calls are made for greater public involvement when society feels their elected representatives are becoming too distanced from the decision-making process.[120] The 1991 reforms reduced patient ('consumer') input through Community Health Councils. Few GP Fundholders devised purchasing plans or involved patients.[121] The NHS Plan will further reduce input via Community Health Councils and eventually replace them with in-house 'patient advocates'[122] even though there is a strong argument in favour of strengthening their role.[123] Society has rights to have its views taken account of through Parliament and via input to local decision-makers such as Primary Care Groups.[124] The media has a role in stimulating debate, educating the public and, questionably, in challenging the government. Healthcare professionals should be involved without one profession being dominant. Nord recognises that public responses are often 'unreflective and unreliable' but believes focus groups which have previously discussed ethical issues provide 'high quality' data.[125] This seems doubtful unless the participants have received appropriate training beyond merely discussing a few issues.[126] The question of who arbitrates when focus groups reach different decisions is also challengeable.

Public participation models may be more likely to identify individual goals and preferences rather than identifying communal goals which maximise welfare. Adopting the Oregon model is impossible and probably undesirable[127] despite suggestions favouring more local population input to increase democracy, 'common-sense' and accountability.[128] Primary Care Groups are likely to perpetuate regional inequalities. As discovered in Oregon, allowing the public to prioritise medical treatments can lead to gross inequity. The process can be manipulated consciously or unconsciously by the selection process of participants. This can be guarded against

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[116]Geschwind, op cit n114 at p359.
[117]Ibid, at p361.
[118]Arbuz, op cit n115 at p5.
[119]Geschwind, op cit n114 at p361.
[120]Most recently following the media coverage of the 'Child B' case: *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.
[121]Audit Commission report: *Fundholding: the main report.* The Stationery Office, London 1996. See also: Stewart-Brown S et al. The problems of fundholding. *BMJ* 1996;**312:**1311-2 at p12.
[122]Department of Health. *The NHS Plan - A plan for investment. A plan for reform.* (Cm 4818 - 1) July 2000 The Stationery Office, London at para 10.19. Available on www.nhs.uk/nhsplan accessed 7 August 2000.
[123]The Association of Community Health Councils for England and Wales prepared a position paper on the culture of health care for the Bristol Inquiry in the deaths of children undergoing heart surgery. This paper argues for the role of the CHC to be enhanced. ACHCEW. Health Perspectives Issue 1/2000 *The Culture of Healthcare.* March 2000, ACHCEW, London. A full copy of their report is available on www.bristol-inquiry.org.uk.
[124]Schwatz L, et al. Rationing Decisions: From Diversity to Consensus. *Health Care Analysis* 1999;**7:**195-205.
[125]Nord E. Towards Cost-Value Analysis in Health Care? *Health Care Analysis* 1999;**7:**167-175,173.
[126]However, if the training lacks impartiality, as in the Cambridge and Huntingdonshire example given by Price, the decision is likely to be the one sought by the training body: Price D. Choices without reasons: citizens' juries and policy evaluation. *J.Med.Ethics* 2000;**26**:272-276 at p272.
[127]It is worth noting that were Britain to consult as widely as Oregon did when constructing its priority lists, we would have had to have '240 public hearings, 940 community meetings and a telephone survey of 20,000'. Dean M. Oregon trail reaches Britain. *The Lancet* 1991:**338:**1133-4.
[128]Some pilot schemes were initiated to elicit the views of the local population regarding healthcare purchase plans. See: Wall A. The Jury is out. *Health Service J.* 18 February 1999 pp32-33; McIver S. *Healthy debate? An independent evaluation of citizens' juries in health settings.* 1999 Kings Fund, London and Davies S et al. *Ordinary wisdom: reflections on an experiment in citizenship and health.* 1999 Kings Fund, London.

by having legislation giving protection against discrimination and abuse of human rights[129] or by having universal input. The NHS Plan[130] followed a bizarre public consultation exercise which purported to discover what 'the people' want from the NHS yet failed to take any measures to solicit responses from some of the most underprivileged groups in society.[131] Some services[132] are rated much lower by the public than by professionals or government and their funding conflicts with 'the political need to respond to the outcry from the press and public for more beds...and more intensive care facilities'.[133] Sykes favours public education before public involvement: '(w)hen they understand the cost and fallibility of many therapies, we should help them to understand that they have a role in choosing which therapy should, and which should not, be 'freely' available in the NHS'.[134] Thus, an educated public could work in a relationship based on trust, not 'benign paternalism', with decision-makers.[135] Others are less convinced this is workable and argue for limitations to public involvement to prevent inequality.[136] Yet, if a local community decides healthcare should be provided on an equality of access basis rather than equality of need perhaps its views should prevail as a democratically legitimate decision.[137] Clinical audit may eventually demonstrate flaws in this approach which could then influence whether local views should be paramount. Resource allocation should be conducted openly and honestly.

5.1.5 The Increased Funding Model

The increased funding model is less a suggestion for improving the decision-making process than an avoidance measure. It blames 'government parsimony'.[138] This has some validity.[139] Britain spends about 5.8% of national income on healthcare,[140] less than comparable European countries.[141] The British system is 'grossly underfunded and underdeveloped compared to other mature industrial democracies'.[142] Appeals through the media and judicial review are made for funds for individual patients.[143] Reducing duplication of services and buildings could redirect money towards treatment, however, outside London, travelling distances are greater

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[129]It is still too early to see whether the more recent Disability Discrimination Act 1995 will have an impact on the access of disabled persons to healthcare and the quality of treatment received. For instance, there is some evidence that patients with Down's syndrome are not receiving appropriate treatment for associated hearing and sight loss. Major S. Parents of people with Down's syndrome report suboptimal care. *BMJ* 1999;**318:**687.

[130]*The NHS Plan,* op cit n122.

[131]Department of Health. *Creating a 21st century NHS.* Internet site: www.nhs.uk/nationalplan accessed 5 June 2000.

[132]For instance, primary care, care in the community and mental health (the Cinderella services).

[133]Sykes P. Just what are you doing? *Health Service J.* July 25 1996 p23.

[134]Ibid.

[135]Coote A. 'Possibilities for direct public involvement in rationing decisions' In New B (Ed). *Rationing. Talk and Action in Health Care.* 1997 Kings Fund & BMJ Publishing Group, London at pp158-164.

[136]Butler J. *The Ethics of Health Care Rationing: Principles and Practices.* 1999 Cassell, London at p112.

[137]For example, a women's magazine advised its readers that one district, City and Hackney, decided that in-vitro fertilization should be made more widely available by limiting the number of treatment cycles per couple to only one. *Woman's Weekly* 11 June 1996. It might mean that the chance per couple is less than if they were able to receive two or three treatment cycles but it would enable those currently denied treatment via the waiting list system, to receive treatment.

[138]Klein, Day & Redmayne, op cit n91 at p97.

[139]The World Health Organisation has recently placed the British healthcare system only 18th in terms of efficiency compared with other countries. World Health Organisation. *The World Health Report 2000 Health Systems: Improving Performance* 21 June 2000 WHO www.who.int/whr accessed 26 June 2000.

[140]World Health Organisation, supra, Statistical Annex, at p195. A marginally higher figure of 5.9% GDP was suggested by Smith four years earlier: Smith D. Quick nurse, more private cash. *The Sunday Times* November 10 1996. A significantly higher figure of 7.1 % GDP was suggested by Rudolf Klein the same year: Klein R, Day P & Redmayne S. *Managing Scarcity: Priority Setting and Rationing in the National Health Service*. 1996 Oxford University Press, Buckingham at p98. Various figures may be quoted for the U.S.A. healthcare budget taking its total spend up to approximately 16% GDP. According to the World Health Organisation, supra, the figure for the U.S.A. is 13.7% GDP although Smith quoted it at about 6.2%.

[141]Germany spends 10.5% GDP; France 9.8 % GDPand the Netherlands 8.8% GDP: World Health Organisation, op cit n139, Statistical Annex. at p195.

[142]Sieverts SH. Is there a crisis in health care. *Pamphlet 574 Health Crisis - What Crisis? Proceedings of the Fabian/Socialist Health Association New Year Conference 1996* 1996 Fabian Society. London at pp11-13.

[143]Judicial review is examined in the next chapter.

and more difficult for those of limited means and mobility. A founding principle of the NHS is equal access to healthcare and public consensus seems to favour local centres providing good care with a few specialist centres. The increased funding model also places emphasis on clinicians becoming more aware of 'opportunity costs' since demand is what doctors choose to make it.[144]

Governments have regularly denied that the NHS is significantly underfunded, despite apparent crisis, thus straining public confidence. The claim that there is 'a gap between resources and demand which shows signs of increasing as we move into the next century'[145] was rejected.[146] The Healthcare 2000 report suggests that an aging population, increasing public expectations and medical advances cannot be coped with by the NHS as currently organised.[147] Healthcare 2000 proposes charges for non-standard services such as private rooms and appointments within a certain period. This would create three-tier healthcare system with a private sector funded by insurance or personal wealth and a two-tier NHS. The private sector calls for recognition that the government's 'primary duty is to ensure that the population has access to adequate health and social care, not necessarily to provide or fund it itself'.[148] It suggests a mixed provision of private, voluntary and state provision and clarity about what the state will fund so 'we can get on with planning our lives to take account of that'.[149] Such views are naïve. Today's elderly believed that they knew what the state would fund. The state alters what it deems to be national priorities. More funding for the NHS is forthcoming but there will always be a point beyond which funds do not exist whoever pays.[150] The NHS is labour intensive. Extra funding will not necessarily produce the personnel needed for more treatment episodes[151] and probably only postpones problems.[152] Even where funds exist, compassion for the individual may require that treatment is withheld or stopped. Increasing funding 'can never be a complete solution'.[153]

5.1.6 Insurance Based Healthcare

This model suggests that Britain can no longer afford to rely solely upon the state providing the majority of healthcare. Therefore, partial adoption of the American model is proposed (or threatened). Private medical insurance was encouraged under the Thatcher reforms and opposed by Labour. However, Tony Blair recently made it clear that either the NHS embraces 'change' or an American model will have to be introduced whereby the NHS only cares for emergency cases and the very old and poor.[154] Such comments fail to recognise that healthcare practitioners have been subjected to numerous changes over the last 25 years.[155] The NHS Plan sets out the reforms.[156]

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[144]Klein R. Dimensions of Rationing: Who Should do What? *BMJ* 1993;**307**:309. See also, Jonsen AR, *The New Medicine and The Old Ethics* 1990 Harvard University Press, London at p97.

[145]Healthcare 2000 Group, Chairperson Sir Duncan Nichol. *Healthcare 2000*. 1995 Healthcare 2000, London.

[146]Department of Health. *NHS:A Service with Ambitions* November 1996 The Stationery Office, London.

[147]Healthcare 2000 Group, op cit n145.

[148]Independent Healthcare Association *Sunday Times* 10 November 1996.

[149]Ibid.

[150]*The NHS Plan*, op cit n122, Summary. Whether the extra funding will be sufficient is challenged by the BMA and others. See: British Medical Association. Healthcare Funding Review February 2001 BMA, London 'Resources' (www.bma.org.uk/public/polsreps.nsf accessed 15 February 2001); Towse A, Sussex J. "Getting UK health care expenditure up to the European Union mean" - what does that mean? *BMJ* 2000;**320**:640-642 and Appleby J, Boyle S. Blair's billions: where will he find the money for the NHS? *BMJ* 2000;**320**:865-867.

[151]Klein, Day & Redmayne, op cit n91 at pp101-102.

[152]Mason JK, McCall Smith RA. *Law and Medical Ethics* 5th Edn.1999 Butterworths, London at p305.

[153]British Medical Association, op cit n150, Chapter 3 'Resources' at p3.

[154]Miles A. Can the NHS be Saved? Last Chance. *The Times* 26 May 2000.

[155]The author of this thesis entered the NHS as a trainee medical laboratory scientist 25 years ago.

[156]*The NHS Plan*, op cit n122.

The state-administered Medicaid-Medicare system results in regional as well as individual inequality. The Oregon experiment attempted to address this.[157] Other healthcare is privately funded, mostly as an employee benefit. America is moving towards 'managed care'.[158] Managed care organisations (MCOs) are mostly non-profit groups which people join by paying fees, or having fees paid by their employer. Most patients now are seen under a managed care scheme.[159] Doctors are expected to balance their patients' needs against their employers' needs.[160] The doctor must consider his/her population of patients not just the individual. Physicians are used as 'gatekeepers' to care much as GPs are in Britain. Buchanan argues that the managed care 'revolution' is based on a 'begrudging and belated recognition that adequate care...cannot be maximal care'.[161] Only cost-effective services are to be provided and the doctor faces a personal financial penalty either based on the cost-implications of the services s/he selects for individual patients or on the managed care organisation's success in meeting its target.[162] Guidelines and protocols restrict physician autonomy much as is intended by NICE. Consequently, Loewy, like Buchanan,[163] reports that Americans have lost trust in their doctors.[164] This mirrors findings in this country.[165] Emanuel blames the growing dominance of managed care organisations for raising 'both expectation and apprehension about improving the justice of the American health care system'.[166] Managed care aims to reduce over-treatment of patients by providing a unified, cost-effective service and educating users into reducing unreasonable demands under threat of huge insurance premium rises. In Canada, which, like Britain, has a universally accessible state-funded healthcare system, Alberta is considering moving to a managed care system which will pay a set fee per patient to physician 'gatekeepers' (equivalent to British GPs).[167] The primary care focus mirrors that of the U.K. but Reay, like Loewy,[168] questions the ethics of expecting doctors to fulfil both a public health and a medical role.[169] The BMA cannot see how insurance-based healthcare could be introduced in the UK without 'compromising the principle of equity'.[170]

5.2 Medical Models

The politico-economic models require the clinician to consider interests other than the patient's. Many clinicians believe the decision to treat/screen a patient should be based 'solely on the needs of the individual patient immediately before him [sic], leaving it to others to allocate resources' and, once started, treatment should continue for as long as it is doing some good.[171] The medical models fall into a variety of groups.

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[157]See discussion earlier.
[158]Medicaid for the poor and Medicare for the very old and disabled. Curtin L. The Ethics of Managed Care - Pat 2. *Nursing Management* 1996;**27**,9:53-55.
[159]Churchill LR. The United States Health Care System under Managed Care. *Health Care Analysis* 1999;**7**:393-411 at p395.
[160]Ibid.
[161]Buchanan A. Trust in Managed Care Organizations. *Kennedy Institute of Ethics Journal* 2000;**10**,3:189-212 at p196.
[162]Churchill, op cit n159 at p395.
[163]Buchanan, op cit n161 passim.
[164]Loewy EH. Health-Care Systems and Ethics: What Can We Learn? *Health Care Analysis* 1999;**7**:309-320,318.
[165]Rogers A et al. "If a patient is too costly they tend to get rid of you:" The Impact of People's Perceptions of Rationing on the Use of Primary Care. *Health Care Analysis* 1999;**7**:225-237.
[166]Emanuel EJ. Justice and Managed Care: Four Principles for the Just Allocation of Health Care Resources. *Hastings Center Report* 2000;**30**.3:8-16 at p8.
[167]Reay T. Allocating Scarce Resources in a Publicly Funded Health System: Ethical Considerations of a Canadian Managed Care Proposal. *Nursing Ethics* 1999;**6**,3:240-250.
[168]Loewy, op cit n164. See also: Loewy EH. Justice, society, physicians and ethics committees: incorporating ideas of justice into patient care decisions. *Cambridge Quarterly Healthcare Ethics* 1996;**5**:559-569.
[169]Reay, op cit n167 at p245.
[170]British Medical Association, op cit n50 Chapter 5 'Mechanisms' at p7.
[171]*BMJ* Legal Correspondent. Rationing of Resources. *BMJ* 1985;**290**:374-5 at p375.

5.2.1 The Medical Expertise Model

Most treatment/non-treatment decisions seem made according to the medical model which concentrates primarily on cure. However, Veatch suggests technology may be used inappropriately because to use it is unnecessary (it over-treats a patient), unsuccessful (using it is futile), unkind (it prolongs life of little quality), unsafe (harms almost certainly outweigh the benefits) or unwise (it is an inappropriate use of resources which could be better used for others).[172] Therefore, an improvement in clinical data and outcomes is needed[173]

Hope et al have revealed that the phrase, 'not clinically indicated' which represents a medical model of decision-making, really has two meanings with a huge difference in their underlying ethics.[174] The first meaning is that treatment is 'not in the patient's interests' and secondly, it is 'not the right use of resources'. The common employment of the term suggests that doctors feel more comfortable implying that the decision is based on a medical model of reasoning. Few patients have sufficient knowledge to challenge scientifically. The balance of power lies firmly with the doctor. Hope indicates that if the doctor believes a treatment option is not in the patient's interests, s/he should '(g)ive relevant information and allow the patient to choose'.[175] However, the information the patient receives can only be as good as the doctor has been given, often by those with vested interests.[176] Recent studies confirm that there is still a 'need to improve the comprehensiveness, relevance and intelligibility of the information given to patients'.[177] Similarly, even when physicians have specifically been given outcomes data little change is visible in the treatment decisions suggesting either that they are prepared to gamble on their patient being in the percentage that may benefit even though the evidence is to the contrary, or that hard evidence is less important than what the doctor may describe as his/her 'own clinical experience'.[178] Dowie argues that medical decision-making is conducted at the most intuitive levels of analysis rather than the scientific level, there being a continuum between intuition (ie. ill-structured) and scientifically analytical (ie. well-structured) decision-making.[179] Dowie proposes greater use of systems to aid judgment such as algorithms, Churchillian lists[180] and computers.[181] He encourages the adoption of the 'decision-tree' approach whereby a problem is broken down into separate uncertainties with probabilities allotted to each branch so that a measure of utility can be accorded to each option but fails to explain how values are to be allocated to each branch. Dowie, though, is rightly critical of the practice of holding expensive inquiries into errors of judgment which fail to produce guidance for future practice.[182] There are concerns that guidance from NICE may not automatically alter clinician's practice. However, NICE guidelines are likely to be taken into account when allegations of negligence are heard by the courts so pressure will be brought to bear upon doctors.[183] Making guidelines compulsory will bring the government into direct conflict with

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[172]Veatch RM. *A theory of medical ethics*. 1981 Basic Books, New York.
[173]It will be the role of NICE to supply this data.
[174]Hope T et al. 'Not clinically indicated': patients' interests or resource allocation? *BMJ* 1993;**306**:379-381.
[175]Ibid, at p379.
[176]Kee F. Patients' prerogatives and perceptions of benefits. *BMJ* 1996;**312:**958-960.
[177]Ibid, at p959.
[178]Poses R et al. You can lead a horse to water - improving physicians' knowledge of probabilities may not affect their decisions. *Medical Decision Making* 1995;**15**:65-75.
[179]Dowie J. 'Decision Analysis: the Ethical Approach to Medical Decision-Making'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester at pp421-434.
[180]A list is made with two columns, on giving the reasons in favour of a particular action and the other the reasons against the action. Then the choice is made according to which column outweighs the other. It is a model supposedly used by Sir Winston Churchill in planning the course of the Second World War. Such an approach was used by Thorpe LJ in *Re A (Male Sterilisation)* [2000] 1 FLR 549 at p560.
[181]Dowie, op cit n179 at pp421-434.
[182]Ibid, at p431. The Bristol Inquiry differs in this respect and interim reports have been issued regarding consent procedures in general and the retaining of human material. See: www.bristol-inquiry.org.uk.
[183]Teff H. 'Clinical Guidelines, Negligence and Medical Practice'. In Freeman M, Lewis A (Eds) *Law and Medicine: Current Legal Issues* Vol 3. 2000 Oxford University Press, Oxford pp67-80.

doctors.

5.2.2 The Medical Need Model

Medical decision-making can be based on perceived need. Like other models it is value-laden and subject to the personal bias of the needs-assessor although portrayed as more neutral. Maxwell considers that the NHS has 'always been committed to meeting health care needs on the basis of need alone, without regard to the ability to pay' but, because resources are limited, it 'becomes important to meet needs at the highest level generalizable to the whole population' (ie. a utilitarian approach).[184] Until the NHS decides whether its goal is equity of access or equity of outcome resource allocation will remain problematic. Maxwell considers that the existing structure is unfair so justice should trump utilitarianism. Butler questions whether access could be reduced in wealthy areas in order to improve access in areas with high morbidity. [185] Williams argues that 'need' should be defined as 'capacity to benefit'.[186] If capacity to benefit is minimal, scarce resources should not be wasted. Difficulty lies in what counts as 'benefit'[187] and separating 'needs' from 'wants'.[188]

Meeting medical need as a model for decision-making can be seen as based on a duty to rescue. Healthcare has a tradition based upon helping the less-fortunate.[189] Whilst there may be an 'imperfect' duty to help others this is not universally accepted or recognised in law. Requiring rescue attempts to be made could be seen as giving one person rights over the liberty of another. Menlowe considers that there are three views regarding rescues: (a) they are never morally required, (b) they are sometimes morally required or (c) there is an extensive requirement to rescue.[190] He concludes that there is an extensive duty to rescue which is obviously a duty of beneficence. Harris similarly suggests, with regard to NHS resource allocation, what is really a duty to rescue.[191] Harris believes that 'there is a good principle that real and present dangers should be met before future and speculative ones'.[192] This would mean that the NHS should prioritise treatment for existing conditions not preventative medicine such as risk-screening or vaccination.[193] Thus, Harris would justify diverting large amounts of resources into lost causes because the immediate need of the premature baby, the person in end-stage renal failure, the person in cardiac arrest would be paramount over all other demands or needs.[194] No thought as to cost or the difficulties of defining such a duty within the constraints of law is apparent. However, the media seemingly agree and run emotive campaigns promoting individual needs for treatment as rights to treatment.[195]

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[184]Maxwell RJ. 'Health care management: are ethics relevant?'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp819-828 at p827.

[185]Butler J. *The Ethics of Health Care Rationing: Principles and Practices.* 1999 Cassell, London at p144.

[186]Williams A. 'Economics, Society and Health Care Ethics'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester at pp829-842.

[187]For example, see: BMA *Withholding and Withdrawing Life-prolonging Medical Treatment* 1999 BMA, London at pp1-2.

[188]Butler J. *The Ethics of Health Care Rationing: Principles and Practices.* 1999 Cassell, London at pp44-46.

[189]For instance, the Florence Nightingale story and the long tradition of nursing religious orders.

[190]Menlowe MA. 'The Philosophical Foundations of a Duty to Rescue'. In Menlove MA, McCall Smith A: *The Duty to Rescue*. 1993 Dartmouth Publishing Co Ltd, Aldershot at pp4-50.

[191]Harris J. Maximising the health of the whole community: the case against. *BMJ* 1997;**314**:669-672. See also, Letters: *BMJ* 1997;**314**:1901-2.

[192]Harris J. Maximising the health of the whole community: the case against. *BMJ* 1997;**314**:669-672 at p672.

[193]In other words, preferencing acute care over primary care.

[194]Harris J. Must doctors save their patients? *J.Med.Ethics* 1983;**9**:211-218.

[195]Canada, which supports the idea of universal rights to healthcare, also suffers regional disparity: Kluge E-HW. The Canadian Health Care System. *Health Care Analysis* 1999;**7**:377-391 at p388.

Culyer has identified six characteristics as necessary in order for 'need' to have any legitimacy: (1) overt recognition that it is value-laden; (2) derivation from the objectives of the healthcare system; (3) ability to be applied in practice to both vertical and horizontal distributions; (4) specificity as to persons and services required; (5) directly linkable to resources; (6) not productive of inequitable results.[196] Hope questions how to decide which needs should take precedence when the healthcare system cannot meet all needs and, if all needs could be met with the existing resources, which benefits should be funded.[197] If need is to be useful more information is required regarding treatment outcomes and 'futility' to avoid subjective quality of life assessments.[198] Outcomes research is still in its infancy and lacks funding. Hope seems to suggest categorising treatments as to whether they are 'needs' or 'benefits', thus enabling resource allocation to be carried out, with larger budgets for 'needs' and lists guiding doctors as to what medical options to consider.[199] This seems appealing but it crudely over-simplifies the position and is little other than 'Oregon'-style priority listing subject to clinicians lobbying in favour of their own specialty. This model cannot satisfactorily resolve the difficulty if the clinician's view differs from the patient's.[200]

5.2.3 Evidence-based models

In the 1970s came the realisation that 'the welfare state could no longer live off the dividends of the growth state'.[201] Consequently, Cochrane's *Effectiveness and Efficiency*[202] and Illyich's treatise on iatrogenic illness[203] have influenced beliefs that 'there would be no need for rationing if only the knowledge generated by science were fully utilized'.[204] No one disputes the futility of offering a kidney to a diabetic patient who will die soon from an inoperable brain tumour[205] or a new liver to a chronic unreformed alcoholic of no fixed abode.[206] Clinical audit[207] and research to identify appropriate care using 'expert opinion and literature'[208] is increasing[209] but is not as neutral as implied. International research and audit may be hampered by the relationship between medicine and culture. Research can reveal natural pools of patients for whom certain treatments are inappropriate[210] and identify those from whom logic dictates treatment should be withheld or withdrawn.[211] By conducting analyses as to costs, efficiency and effectiveness of procedures it is believed that informed

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[196]Culyer AJ. Need: the idea won't do - but still we need it. *Soc.Sci.Medicine* 1995;**40,**6:717-730 at 727.
[197]Williams, op cit n186 at p380.
[198]Saunders J. Medical futility: CPR. In Lee R, Morgan D (Eds) *Death Rites: Law and ethics at the end of life.* 1994 Routledge, London at pp72-90 at p85. See also: Zucker MB, Zucker HD. *Medical futility and the evaluation of life-sustaining interventions.* 1997 Cambridge University Press, Cambridge.
[199]Hope T et al. 'Not clinically indicated': patients' interests or resource allocation? *BMJ* 1993;**306**:379-381 at p380.
[200]For instance, Culyer cites the example of a patient with cancer of the larynx. Irradiation may preserve the voice but the success rate is lower. Surgery is more efficient, survival rates are better, but the voice is lost. Culyer, op cit n196 at p728.
[201]Klein, Day & Redmayne, op cit n91 at p43.
[202]Cochrane A. *Effectiveness and Efficiency.* 1972 Nuffield Provincial Hospitals Trust, London.
[203]Illich I. *Limits to Medicine: Medical Nemesis - The expropriation of health.* 1976 Penguin, Harmondsworth.
[204]Klein, Day & Redmayne, op cit n91, at p97.
[205]Collins EG, Pfeifer B. Decisions not to transplant: futility or rationing. *J.Cardiovascular Nursing* 1995;9:23-29 at p27.
[206]Ibid, at p28.
[207]Defined by the Department of Health as 'The systematic critical analysis of the quality of medical care, including the procedures used for diagnosis and the treatment, the use of resources, and the resulting outcome and quality of life of the patient.' DoH. *NHS Review Working Paper No 6* (1989) HMSO, London.
[208]Dr Nicholas Hicks, Consultant in Public Health Medicine, Oxfordshire HA. In *Health Care: Resources, Choices and Decisions,* op cit n14 at p12. Klein et al report that only 15% of medical interventions are supported by solid scientific evidence. Klein, Day & Redmayne, op cit n91, at p92.
[209]The Cochrane Database is one such resource now available on-line in this country. A similar project is being conducted by the RAND Corporation in America. For a comment on the RAND study see: Sharpe VA, Faden AI. *Medical Harm: Historical, Conceptual, and Ethical Dimensions of Iatrogenic Illness.* 1998 Cambridge University Press, Cambridge at pp214-5 and Rivett G. *From Cradle to Grave: Fifty years of the NHS.* 1998 Kings Fund, London at pp300-301. The National Institute of Clinical Evidence (NICE) will fulfil a similar role.
[210]Braithwaite BD. NATALI - a model for National Computer Databases in the investigation of new therapeutic techniques. *J.Royal Soc.Med.*1995;**88**:511-515. See also: Rogers L. Doctors admit three in four operations are unnecessary. *The Sunday Times* 27 November 1994.
[211]However, audit will not always be conclusive. For example, see the debate over digoxin for heart attacks: Our Health Correspondent. Foxglove dispute proves incurable. *The Times* 27 August 1996.

choices can be made.[212] However, a solely clinical or economic focus can lead to unfairness for the individual by failing to take account of individual need or circumstances.[213] Mapping the human genome[214] will lead to discriminatory practices within healthcare.[215] Delivering inappropriate healthcare contributes to rising costs.[216] Chantler advocates that health professionals should 'work out (the) choices with families'[217] but every premature baby, every disease or accident victim is potentially a tragedy and a triumph.[218] One person can swing the decision-making process in the direction of his/her beliefs and a possibly hidden agenda. For example, research has shown that 98 % of PVS patients with corpus callosum lesions in their brain never recover.[219] However, of the PVS patients who did recover, 24 % of them had those same lesions.[220] If relatives are only told the first fact, they will be more likely to opt for non-treatment. Similarly, if no SCBU[221] cot is available, the doctor may be less honest about all the treatment alternatives for a premature baby. The level of maternity care purchased may influence the decision whether to treat or not.[222] Yet some might argue that, 'where there is life, there is hope' so 'everything that can be done, should be done', regardless of cost. Consequently, the use of 'futility' when advising non-treatment can be dishonest. By interpreting 'patient survival' as 'survival to discharge'[223] it is easier to designate treatments as 'futile' and 'clinically inappropriate'.[224] Raising the threshold of 'futility' means that decisions to withhold or withdraw treatment will have already been made since it is inappropriate for hospitals or doctors to 'offer treatments for which there is no evidence of effectiveness'.[225] If evidence-based medicine is to be practised, doctors must be prepared to deliver care in line with the latest data.[226] This may conflict with the patient's best interests by placing science above ethics or law.[227] As Frith points out, medical literature discussing evidence-based practice rarely identifies the part values can play in decision-making.[228] Evidence-based practice could mean compulsory treatment or penalties for those who impose additional burdens on the rest of society because of their rejection of recommended treatment or preventative measures such as vaccinations. Yet, currently, if a treatment is

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[212]Rivett G. *From Cradle to Grave: Fifty years of the NHS.* 1998 Kings Fund, London at p382.

[213]This seemed to be the root of the public disquiet regarding the Child B case - *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055. Dickenson briefly discusses this point in Dickenson D. Can Medical Criteria Settle Priority-Setting Debates? The Need for Ethical Analysis. *Health Care Analysis* 1999:**7:**131-137.

[214]Announced on 27 June 2000: Macintyre B. Opening the book of life. *The Times* 27 June 2000.

[215]Cedar S, Terry L. Genes and Genealogy. *Family Law* 2000;**30:**744-747.

[216]Rivett G. *From Cradle to Grave: Fifty years of the NHS.* 1998 Kings Fund, London at p299.

[217]Chantler C. In *Health Care: Resources, Choices and Decisions,* op cit n14 at p7.

[218]For one such triumph see: Wilkinson P. School at last for the 1lb baby who fought for life. *The Times* 10 January 2000.

[219]Andrews K. Prediction of recovery from post-traumatic vegetative state. *Lancet* 1998; **351:**1751.

[220]Ibid.

[221]Special Care Baby Unit.

[222]In October 2000, the author of this thesis was told of a pregnant woman who alleges that she was turned down for maternity care by several London hospitals because the foetus had Edwards Syndrome and she refused to have an abortion because of her religious beliefs. She had to travel to the outskirts of London where a hospital agreed to book her in and the child was delivered in May 2000. He was not expected to live beyond a year and the mother spent most of her time with him in hospital before his death at five months. The mother seemed deeply suspicious of the motives of doctors and consequently numerous complaints were lodged against staff members. Personal communication. The mother has now taken her complaints to the media: Horsnell M. Parents say hospital chose to let baby die. *The Times* 27 November 2000.

[223]In one survey, survival post-cardio-pulmonary resuscitation was 78% when measured as successful restoration of heartbeat and breathing but only 11% when measured as discharge from hospital for the same group of patients: Editorial. Failure of 'Predictors' of Cardiopulmonary Resuscitation Outcomes to Predict Cardiopulmonary Resuscitation Outcomes: Implications for Do-Not-Resuscitate Policy and Advance Directives. *Arch.Intern.Med.*1993;**153:**1293-6,1293.

[224]Harper W. The role of futility judgments in improperly limiting the scope of clinical research. *J. Med.Ethics* 1998; **24:**308-313.

[225]Ibid at p311.

[226] Stewart-Brown S et al. The problems of fundholding. *BMJ* 1996; **312:**1311-2. See also the findings of the Audit Commission: Audit Commission report: *Fundholding: the main report.* The Stationery Office, London 1996. Vivienne Harpwood describes how league tables of clinical performance and the trial of the PRODIGY computer-based system for making available the latest prescribing advice to doctors is likely to impact upon clinical practice: Harpwood V. 'The Manipulation of Medical Practice.' In Freeman M, Lewis A (Eds) *Law and Medicine: Current Legal Issues* Vol 3. 2000 Oxford University Press, Oxford pp47-66, in particular at pp56-58.

[227]See, for example, the discussion, later in this thesis, regarding the approach taken towards establishing best interests in *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.

[228]Frith L. Priority Setting and Evidence Based Purchasing. *Health Care Analysis* 1999;**7:**139-151, 141.

effective there is no obligation for it to be provided.[229]

Predictions as to the quality of life after treatment may be decisive. If the quality of life is likely to be poor, the cost may be considered too high either by the patient, his/her carers or the healthcare team. A crucial question under this model is whose opinion is decisive. Most decisions are based upon the possibility of cure probably because medical education encourages doctors to see 'curing' the patient as the primary goal of medicine.[230] Fox suggests this model ignores other valuable goals such as prevention of ill health, pain and symptom relief, and palliative care.[231] Ignoring these can lead to over-treatment. There is a danger that linking 'cure' as the predominant medical model with cost-effectiveness means only treatments offering high probabilities of 'cure' will be funded.[232] Curative models of care rely heavily upon scientific evidence with 'objective' laboratory evidence being preferred to 'subjective' patient report.[233] The 'reverence for hard science can lead to patients being treated less as whole persons than as repositories for disease.'[234] The model assumes that, if a cure is possible (ie. treatment is effective) the patient will accept treatment so patient refusal is regarded as mis-guided or obstructive.[235]

In contrast to the curative model of care the 'palliative' model acknowledges that not all patients can, or desire to, be cured.[236] Patient-centred, it focuses on how providing care or treatment can reduce pain, restore functional ability and control the symptoms of disease. The goals are those the patient deems important. It does not consider death as physician-failure. Time is needed to construct a relationship with the patient, jointly discovering what goals are important so health care systems based upon efficiency preclude holistic decision-making becoming more widespread.

Predicting health state following treatment/non-treatment requires assessing the patient's quality of life and is usually conducted by those with the power to give or withhold treatment not the patient. Fairbairn suggests 'quality of life' is employed differently with handicapped neonates from the elderly or terminally ill. Consequently, the enforced death of neonates and handicapped children is allowed but terminally ill adults have to 'endure enforced life'.[237] Fairbairn considers decisions look as if they are about the futility of treatment for individual babies but 'really they are about the quality of life of someone else'.[238] This point is important as decisions to opt for aggressive (curative) therapy after birth usually rests with the parents and whether they

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[229]As NICE (the National Institute of Clinical Excellence) reports on the effectiveness of various treatments, 'postcode rationing' may decline, particularly if the government is prepared to issue purchasing guidance as it has recently in the cases of Taxol and Tamoxifen: NICE Press Release: NICE Issues Guidance on Taxanes for Ovarian Cancer. NICE 2000/013, 5 May 2000 www.nice.org.uk/updates/upd_ind.htm accessed 14 June 2000. Outcry followed its failure to recommend the taxanes for breast cancer as well: Marsh B. Ordeal for thousands over breast cancer drug. *Daily Mail* 6 May 2000.

[230]Fox E. Editorial: Predominance of the Curative Model of Medical Care. *JAMA* 1997;**278**:761-3.

[231]Ibid, at p761.

[232]The definition of 'cure' given by Pellegrino and Thomasma has been adopted for this thesis: Pellegrino ED, Thomasma DC. *Helping and Healing*. 1997 Georgetown University Press, Washington DC at p27.

[233]Fox, op cit n230 at p761.

[234]Ibid, at p762.

[235]Doctors may then ask the courts to compel treatment as in *R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728. There is also an element of medical possessiveness once treatment has begun and doctors can be reluctant to allow patient's subsequent preferences to prevail: Chapman J, Hussell L. Two years ago, this man underwent the first hand transplant. How did he show his gratitude? By refusing to take his vital medication and asking for the hand to be removed. *Daily Mail* 21 October 2000. See also, the possessiveness over the conjoined twins evident in *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 (discussed in next chapter).

[236]According to the World Health Organisation, palliative care is 'the active total care...of patients whose disease is not responsive to curative treatment'. WHO *Cancer Pain Relief and Palliative Care: Report of a WHO Expert Committee*. 1990 WHO Geneva, Switzerland. I would extend the definition to include the active total care of patients who choose not to undergo attempts to cure their condition. Those whose decision is informed should not be denied palliative care simply because they have taken a different view from the medical specialists.

[237]Fairbairn G. Enforced life:enforced death. *J.Med.Ethics* 1991;**17**:144-9 at p144.

[238]Ibid.

feel able to cope.[239] Fairbairn suggests that, since it is impossible to obtain a subjective viewpoint from the neonate, decision-making could be improved by building up a database of quality of life assessments from people with a range of disabilities or by waiting until the neonate was able (if possible) to express a view. The difficulty with the former is that it would only be possible to collect data from those with sufficient mental capacity to understand the full implications of the question. Those whose lives are closest to the neonates for whom such decisions are made would be unable to provide insight.[240] Likewise, waiting could condemn some neonates to a life that is intolerable. Fairbairn considers this preferable to the current situation of aborting disabled babies or allowing them to die after birth. He seems to suggest abortion is inappropriate because 'greater certainty about the child's condition is possible after birth than before' and that infanticide is preferable to abortion.[241] This argument implies that if enough people with disabilities similar to the foetus`s considered their lives worth living, the pregnancy must continue regardless of the mother's wishes. This unsustainable argument would reduce women to incubators. Most disabled people would predictably favour the life they have rather than no life. The resulting model would be distorted by the subjective bias of those who, because they have faced certain problems, feel they have an authoritative view upon such dilemmas in the lives of others.[242]

Whether predictions of health state after treatment should be used to choose between patients is problematic. If, as Harris says, 'each life is valuable,'[243] the model must be unworkable because it unfairly weights the decision in favour of the patient whose health state is closest to the norm. Nord indicates that in Norway there is a 'strong adherence in general to the principle of equal entitlement to treatment' regardless of health state afterwards.[244] Nord criticises the failure to recognise that in most Westernised countries the general public see the lives of children as more valuable than other lives.[245]

It seems apparent that there is a difference between decision-making models (such as QALYs) which rely upon an estimation of patient health status with/without treatment and those relying upon a prediction of outcome but others may consider the two identical. The former seem to look for evidence of improvement in health state to something approaching 'good health' and discriminate against those who will never enjoy 'good health' because the underpinning principle is primarily an economic one. Outcomes research, in contrast, focuses upon collecting clinical data about various condition-treatment pairs and using this as a model to inform the decision. The underpinning principle is primarily scientific. However, more openness about who is included in studies of outcomes is needed. For instance, the tendency to withhold resuscitation from elderly patients is based on aggregate results of survival to discharge even though there is evidence that survival to discharge and survival up to three years post discharge for certain conditions is just as good in elderly patients as younger ones.[246]

Treatment decisions based upon scientific evidence are probably more acceptable to doctors. The difficulty is

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[239]Brahams D, Brahams M. The Arthur Case - a proposal for legislation. *J.Med Ethics*1983; **9**:12-16.
[240]See, for instance: Davis A. A right to life of handicapped.(letter) *J.Med Ethics* 1983;**9**:181.
[241]Fairbairn G. Enforced life:enforced death. *J.Med.Ethics* 1991;**17**:144-9 at p145.
[242]This criticism can be levelled at Fairbairn himself whose views have obviously been framed by his own experiences concerning the birth of a child whose disabilities were incompatible with life and for whom he wishes infanticide had been an option rather than a mere omission to treat curatively: Fairbairn, op cit n241, at p146.
[243]Harris J. QALYfying the value of life. *J.Med.Ethics* 1987;**13**:123.
[244]Nord E. The relevance of health state after treatment in prioritising between different patients. *J.Med.Ethics* 1993;**19**:37-42 at p39.
[245]Ibid. This would apply in this country and also in Sweden according to Nord (at p41).
[246]Rosin AJ, Sonnenblick M. Autonomy and paternalism in geriatric medicine: The Jewish ethical approach to issues of feeding terminally ill patients, and to cardiopulmonary resuscitation. *J.Med.Ethics* 1998;**24**:44-8.

for doctors to realise when their dedication to good science is being consciously or unconsciously affected by economic values. In the U.S.A., a federal agency researches medical outcomes following different treatment interventions and develops practice guidelines to guide future treatment decisions.[247] It has identified that the way physicians determine need for hospitalisation, via a clinical threshold 'test', depends upon the supply of beds. Thus a lack of resources can produce either cost-effective practice or a lowering of clinical standards, for instance, by accepting that the patient may do less well outside hospital.[248] As Wennberg expressed it, 'the rules governing the use of hospitals...are thus determined more by behavioural accommodation to the available supply than by recognised medical theory'.[249] This 'behavioural accommodation' can be unconscious and is then possibly most dangerous.[250] One aspect of the 1991 reforms was to modify clinical practice so that ultimately an acceptance of limited resources would enter doctors' psyche. This is worrying because it means patients may not be told all the available options, not because doctors are 'playing God' but because they are unaware of their behavioural modification.[251] Stoll warns, 'the presence of paternalism or prejudice may colour the doctor's presentation to the patient of the alternatives to hospitalisation, investigation or treatment.'[252] The invoking of therapeutic privilege to justify not involving the patient should be subject to a higher threshold than is currently evident.[253] Some of the consultants interviewed recognised this and expressed ethical concern over whether to tell patients particular treatments were available but they were not allowed to use them. Others were silent on the point which could mean that they saw no ethical need to provide full information about treatment options. This risk could be overcome by ensuring complete openness about what the clinical options are without considering costs. No one knows what demand there would be 'if patients were fully informed of their options and if the probabilities of the various outcomes were presented to them comprehensively.'[254]

5.2.4 The Responsible Body of Medical Opinion Model

This model relies upon a peer approach to a particular decision-making problem. It is comforting since the English judiciary are reluctant to hold a doctor has made an error of judgment providing his or her actions are in accordance with a 'responsible body of medical opinion'. Professional rules may receive judicial approval.[255] Consequently, professional bodies often try to regulate everyday practice through guidelines.[256] Scientific knowledge is preferenced over laymanship. The guidelines model is a favourite tool of professionals, since they are the possessors and interpreters of their particular realm of learning, making it hard for outsiders to challenge. Dressing their expertise in quasi-rules makes it even harder. Rules carry authority. The rise of healthcare economics can be seen as a scientific (mathematical) challenge to medical science but it lacks the authority of professionalism.[257] Guidelines can be useful in educating practitioners regarding changes in

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[247]The Agency for Health Care Policy and Research. Wennberg J.E. Outcomes research, cost containment, and the fear of health care rationing. *New Eng.J.Med.* 1990;**323**(17):1202-4. It is probable that the new agency, NICE, has been modelled on this.

[248]One of the consultants interviewed for this thesis indicated that lack of haemodialysis (in-hospital) slots meant patients were offered CAPD (continuous ambulatory peritoneal dialysis) as the 'preferable' option.

[249]Wennberg, op cit n247 at p1203.

[250]This point is recognised by Stoll who points out that 'medical decision-making may...be based on subconscious value judgements.': Stoll BA. Choosing between cancer patients. *J.Med Ethics*1990;**16**:71-74 at p71.

[251]Stoll BA. Choosing between cancer patients. *J.Med Ethics*1990;**16**:71-74.

[252]Ibid, at p72.

[253]See: Florin D. 'Do not resuscitate' orders: the need for a policy. *J.Roy.Coll.Phys.* 1993;**27,**3:135-8, 135.

[254]Wennberg, op cit n247 at p1203.

[255]For instance, *Re R (Adult: Medical Treatment)* [1996] 2 FLR 99 which considered the use of Do Not Attempt Resuscitation orders.

[256]The Royal College of Paediatrics and Child Health recently issued guidelines on withholding and withdrawing life-saving treatment in children. Royal College of Paediatrics and Child Health. *Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice*. September 1997 RCPCH, London. Similarly, the British Medical Association and Royal College of Nursing have issued guidelines on resuscitation and when it may be appropriate to either withhold any such attempt or when to cease: BMA. *Decisions relating to cardiopulmonary resuscitation: A statement from the BMA and RCN in association with the Resuscitation Council (UK)*. 1999, BMA, London

[257]There are no Royal Colleges of Healthcare Economists.

thinking and practice. They may be ill-constructed or badly applied, for instance, used without thought[258] or without due consideration to factors differing from the situation for which the guidelines were drafted.[259] The proposed healthcare reforms look set to validate the scientific model of decision-making with government support for clinical governance and the introduction of NICE to 'produce clear guidance for clinicians'.[260]

Later in this thesis, current proposals for improving the decision-making process will be examined. However, it is worth examining the views of the Tavistock group which has produced the Appleton International Conference guidelines as possibly representative of the approach taken by doctors as a professional body.[261] Like most guidelines, it is useful in setting out good practice. However, it advocates that a doctor need not provide treatment if it entails 'according to the norms of medical practice, loss of function, mutilation or pain disproportionate to benefit'.[262] This is unexceptional if the treatment requested were female circumcision.[263] It is less clear that withholding treatment because of a prediction that the resulting pain will outweigh benefit is not simply 'unbridled doctor paternalism'.[264] It is also problematic given that doctors' attitudes towards death can influence whether they are prepared to try to conquer it when the chances of success are minimal. If death is equated with 'failure' some doctors prefer not to try rather than fail.[265] Also, despite objections, the Appleton guidelines state that '(d)octors have an obligation to try to provide treatment and care that will result in a peaceful, dignified and humane death with minimal suffering'.[266] To find a pro-euthanasia stance enshrined upon the views of only 62% of delegates seems inappropriate since guidelines are intended to shape the practice of those with less experience.[267] It could become a case of guidelines shaping medical ethics, and possibly the law, rather than the reverse. It advises that 'substituted judgment' should be used with incompetent patients and only if this fails should the decision be made using the 'best interests' approach.[268] Given that English law requires decisions to be made in the patient's 'best interests'[269] the guidelines seem to attempt to shape the laws of countries taking differing approaches rather than reflecting the law as it is. This was possibly due to the lack of legal input.[270] Guidelines must reflect the law of the country in which they are being used otherwise decision-makers may find themselves outside the law even though their practice is in accordance with a reasonable body of their fellow professionals.[271] The Tavistock group likewise rejects 'the thinking behind the 'Baby Doe Rules' proposed by the US Federal Government'.[272] In contrast, the *Hastings*

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[258]See: Smith DH, Veatch RM, (Eds). *Guidelines on the Termination of Life-Sustaining Treatment and Care of the Dying: A Report by The Hastings Center*. 1987 Indiana University Press, Bloomington and Indianopolis, U.S.A. at p13.

[259]For example, two of the doctors interviewed for this thesis described the situation of a patient on ventilator support who 'didn't quite meet the criteria for brain stem death' yet they wanted to turn off the ventilator despite this.

[260]*A First Class Service*, op cit n2, para 1.15. What is not yet clear is which will take precedence when there is conflict, the scientific model or the cost-effectiveness model.

[261]Stanley J.M. The Appleton International Conference: developing guidelines for decisions to forgo life-prolonging medical treatment. *J.Med.Ethics* 1992;**18** Supplement. The guidelines are divided into four parts. Part I considers the situation of patients who have decision-making capacity or who have executed an advance directive (pp6-9). Part II relates to patients who lack decision-making capacity and who have not executed an advance directive (pp10-12). Part III sets out guidelines for decisions where the patient has never had decision-making capacity (pp13-15). Part IV concerns decisions to forgo life-sustaining treatment 'under conditions of scarcity' (pp16-21). See also: Smith R. Shared ethical principles for everybody in health care: a working draft from the Tavistock Group. *BMJ* 1999;**318:**248-251 for a restatement of the ethical underpinning of the Tavistock group's guidelines.

[262]Ibid, at p6 Part 1:3b.

[263]Which is unlawful anyhow in both the U.K. and U.S.A.

[264]See note 9 to Part 1 by Brady H. In Stanley J.M. The Appleton International Conference: developing guidelines for decisions to forgo life-prolonging medical treatment. *J.Med.Ethics* 1992;**18** Supplement at p8.

[265]Harper W. The role of futility judgments in improperly limiting the scope of clinical research. *J. Med.Ethics* 1998; **24**:308-313 at p311.

[266]Stanley, op cit n261 at p6.

[267]Ibid, at p7. Caution needs to attend the development of any such guidelines by NICE.

[268]In other words, if it impossible to make a decision based on the exploration of 'what would the patient decide for him/herself?' then the principles of beneficence and non-maleficence are given paramountcy.

[269]The position taken by English courts is discussed in the next chapter.

[270]It is worth noting the finding, reported later, that a number of the consultants interviewed for this thesis rejected the concept of lawyers or ethicists having a legitimate input into such debates.

[271]In other words, they would not be acting 'negligently': *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

[272]Stanley, op cit n261 at pp14-15. The 'Baby Doe Rules' rejected quality of life judgments as a basis of making decisions.

Center guidelines state categorically that they have been 'attentive to the state of the law' and continue: 'these Guidelines are no substitute for legal advice and users of this document should find out how the law in their jurisdiction bears on the recommendations'.[273] Whilst comment is acceptable it seems uncompromisingly autocratic for any group to promulgate rules directly conflicting with a democratically-elected legislature. Clinicians must accept that society may not agree with them.

The last section of the Tavistock guidelines recognises that life-sustaining treatment may be withheld by government agencies because of a shortage of resources[274] or costs outweighing benefits.[275] Although it is clearly the intention of the authors to create guidelines in this area it is merely, at present, a reflective statement. For any guideline to be compelling, the group devising it must have the authority to ensure compliance[276] otherwise it is merely a recommendation from one group, whose views may or may not be worth considering, to another which has discretion to follow or ignore this advice.[277]

Doctors are unlikely to act contrary to guidelines issued by their professional body.[278] The present government is aiming to utilise this by involving doctors in a scientific search to discover which treatments are clinically effective. Their main value is as 'an indication to everyone concerned that decisions about the use of technology should depend on explicit policies, rather than on the intuition or prejudice of individual clinicians'.[279] However, even where there is good data supporting a particular treatment approach, there can be clinicians who would ignore data that 'conflicted with some vague concept of what they considered (or believed others might consider) to be good ethical medical practice'.[280]

5.3 Ethical Models

Unlike the politico-economic or medical models, the models discussed in this section are patient-centred and underpinned by social values and ethical principles such as autonomy, beneficence and non-maleficence.[281]

5.3.1 Patient preference

Patient preference is an important model. If the patient has decision-making capacity their preferences should be considered but even if they lack capacity weight can be accorded to what their preferences might be via devices such as advance directives, deciding 'in the patient's best interests' or 'substituted judgment'.

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[273]Smith DH, Veatch RM, (Eds). *Guidelines on the Termination of Life-Sustaining Treatment and Care of the Dying: A Report by The Hastings Center.* 1987 Indiana University Press, Bloomington and Indianopolis, U.S.A. at p3.
[274]Both financial and material shortages eg. organs for transplantation or hospital beds.
[275]Stanley, op cit n261 at p16.
[276]The professional body can compel its members under threat of sanctions for non-compliance.
[277]Under the 1990 reforms, the power of the healthcare purchasers was derived from the authority vested in the Secretary of State for Health by Parliament.
[278]The BMA recently issued guidance on the withholding and withdrawing of medical treatment. BMA *Withholding and Withdrawing Life-prolonging Medical Treatment.* June 1999 BMA, London. These guidelines are examined in detail in a later chapter.
[279]Jennett B. 'Medical Technology, Social and Healthcare Issues'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp861-884 at p871.
[280]Ibid.
[281]Beauchamp TL, Childress JF. *Principles of Biomedical Ethics* 4th Edn. 1994 Oxford University Press, Oxford.

5.3.1.1 Autonomous Patients

The principle of autonomy upholds the concept that patients should make their own healthcare decisions. It can be seen as a 'form of personal liberty of action, where the individual determines his [sic] own course of action in accordance with a plan based on his own thoughts and decisions'.[282] Spriggs suggests that '(a)s autonomous agents we are "essentially purposive" and we seek ways to effect our short and long term goals'.[283] Such an agent is 'independent, rational and possesses personal integrity'.[284] Regarding validity of consent, it requires that the patient be informed about treatment options, side effects and risks.[285] Patients should also be informed if treatment options are restricted on cost grounds since otherwise their ability to act autonomously is compromised.[286] However, Hall's proposed 'dignitary tort' that would require express prior consent to rationing and treatment-limiting decisions over-emphasises individual rights and encourages litigation.[287] The alternative, a presumption that NHS users give implied consent to rationing, is equally unattractive when regional variations exist. A balance between individual autonomy and societal interests within a resource like the NHS is needed.

Assessing whether a patient has the requisite capacity to act autonomously is problematic.[288] The doctrine of informed consent is based on a recognition that autonomy is vitally important. Those who have capacity should be enabled to have their views heard. In today's technological world it seems barbaric that anyone's views should be ignored because of surmountable communication barriers.[289] With the Western world facing a huge movement of displaced people ways to enhance communication within a healthcare setting need to be actively sought. The patient might find it hard to understand why the doctor held back from providing treatment.[290]

Occasionally a patient may request treatment which the doctor opposes but there is no compulsion for the doctor to comply. The patient's preference has little weight even when the choice is between curative treatment and palliative because often the full range of treatment options is not disclosed to the patient when the doctor has decided that evidence, or experience, is against continuing active treatment. The doctrine of 'therapeutic privilege' may be relied upon by the doctor both to protect the patient and to prevent requests for 'inappropriate' treatment to be given.[291] However, patient preference may be met if treatment is funded privately suggesting evidence-based practice or 'practice in accordance with a responsible body of medical opinion' may be displaced by the desire to generate income.[292] Geographical divisions in healthcare provision

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[282]Greaves DA. Can compulsory removal ever be justified for adults who are mentally competent? *J.Med.Ethics* 1991;**17**:189-194 at 191.
[283]Spriggs M. Autonomy in the face of a devastating diagnosis. *J.Med.Ethics* 1998:**24:**123-126 at p124.
[284]Ibid.
[285]However, the amount of information given is not necessarily comprehensive: see, for example, *Sidaway v Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital* [1985] AC 871.
[286]Harris RA, Nease RF. The importance of patient preferences for comorbidities in cost-effectiveness analyses. *J.Health Economics* 1997;**16:**113-9.
[287]Hall MA. Informed Consent to Rationing Decisions. *The Millbank Quarterly* 1993;71,4:645-668 at p661.
[288]The legal approach to capacity is considered in the next chapter.
[289]Stephen Hawking's computerised voice is well-known to millions of people. Many other patients with similar disabilities do not have access to the same technology.
[290]The author of this thesis was recently told by a midwife of a Kosovan refugee woman who was in labour. The baby's heartbeat started to weaken and the team knew they had to perform an emergency Caesarian section to save it. The woman spoke no English. Her husband knew a few words but the obstetrician and midwives were unable to explain what was needed so he could translate. The British Telecom translation service had been contacted as had the hospital interpreter but after 40 minutes they were still waiting. Eventually the obstetrician went ahead without consent but it was too late to save the baby's life.
[291]For example, Wear and Logue describe a patient whose quality of life seemed intolerably poor yet she continued to refuse to allow a Do Not Resuscitate order being made. Her 'preference' was for the life she had rather than no life at all. Wear S, Logue G. The Problem of Medically Futile Treatment: Falling Back on a Preventative Ethics Approach. *J.Clinical Ethics* 1995;**6,2**:138-148 at p142.
[292]See, for example, Devettere R. *Practical Decision Making in Health Care Ethics: Cases and Concepts* 1995 Georgetown University Press, Washington DC at pp181-182 and Ham C, McIlver S, *Contested Decisions: Priority Setting in the NHS* 2000 King's Fund Publishing, London at p13.

may mean that patient preference is met in one area but not in another. Who the patient's consultant is can also be important. There can be apparently identical patients on the same ward receiving very different treatment. Patient preference will be met when it concurs with the doctor's opinion. Weir believes patients should proactively seek physicians 'willing to adhere to their informed preferences' and be prepared to 'change physicians or...initiate legal action'.[293] If necessary they should 'sign a waiver or release form'.[294] However, problems could arise when a patient has found a physician 'buddy' but their shared views are out of step with accepted medical, ethical and legal opinion.

Patient preference for certain treatment options often depends upon the patient's attitude to risks and benefits.[295] This indicates that for the right choices to be made, the patient must be actively involved in the decision-making process and given the necessary information to weigh up risks and benefits for him/herself. Wennberg demands a model of healthcare that 'disentangles the preferences of the patient from those of the physician'.[296] The model should also 'disentangle' patient preferences from those of health care managers.

Some autonomous patients may refuse treatment - their preference differs from the doctor's opinion. Some refusals are based on religious beliefs and, even where the treatment is life-saving, will usually be upheld in this country.[297] In such situations, the patient preference model is paramount even though it is tantamount to suicide. Some would question whether a refusal of life-saving treatment on religious grounds can ever be valid due to the allegedly 'controlling' nature of some religious groups.[298] It seems clear that society accepts that enforcing treatment, when there is no threat to public safety, constitutes excessive use of state power and illegitimate interference with the privacy of the individual. Weir favours supporting autonomy by informing patients 'about the legal right to refuse medical treatment'.[299] However, whilst society (via its courts) may accept a competent patient's refusal of treatment, the clinician whose expertise has been rejected may be inclined to consider that the patient was, after all, incompetent and so may try to enforce his/her views on the patient.[300] A sensitive exploration of whether the stated views are really the patient's own may be acceptable.[301] 'Bullying' the patient is paternalistic rejection of patient autonomy. The acceptance that there should be no undue interference by the state has a pragmatic element. If the state is paying, it makes economic sense not to force treatment on reluctant patients unless refusal offends society in some way.[302]

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[293]Weir RF. *Abating Treatment with Critically Ill Patients: Ethical and Legal Limits to the Medical Prolongation of Life.* 1989 Oxford University Press, Oxford at p100.

[294]Ibid.

[295]Wennberg J.E. Outcomes research, cost containment, and the fear of health care rationing. *New Eng.J.Med.* 1990;**323,**17:1202-4 at p1202.

[296]Loc cit.

[297]For instance, an adult Jehovah's Witness's refusal of a blood transfusion will not be overturned as a rule by the courts although this principle is not always absolute as will be discussed in a later chapter.

[298]Muramoto O. Bioethics of the refusal of blood by Jehovah's Witnesses: part 1. Should bioethical deliberation consider dissidents' views. *J. Med.Ethics* 1998;**24:**223-230 and Muramoto O. Bioethics of the refusal of blood by Jehovah's Witnesses: part 2. A novel approach based on rational non-interventional paternalism. *J. Med.Ethics* 1998;**24:**295-301. A response is provided by Malyon who argues that 'faith transcends rationality'. Malyon D. Transfusion-free treatment of Jehovah's Witnesses: respecting the autonomous patient's rights. *J. Med.Ethics* 1998;**24:**302-307.

[299]Weir, op cit n263, at p100.

[300]See, for instance, *R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728 and Wilks I. The debate over risk-related standards of competence. *Bioethics* 1997;**11,**5:413-426, in particular at p413. See also, the discussion in *Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389 at pp403H-404A per Thorpe LJ.

[301]The author of the thesis was told of a mother who had just given birth to her fourth child and suffered a post-partum haemorrhage. With her family present she refused blood and received non-blood products which were not expected to be sufficient to save her life. When alone she admitted that she did not want to die because her children needed her but if she had the transfusions she would be an outcast and her husband and family would not let her see her children. A way to carry out secret transfusions overnight without the family or any other patients knowing was found and the woman recovered. Personal communication.

[302]Examples of refusals which might be held to offend society are the refusal of pregnant women to agree to clinically recommended Caesarean sections or the refusal by parents of minor children to allow life-saving treatment. What is considered offensive will depend upon the society in which the refusal is made. For instance, the refusal of a young woman to be 'circumcised' might offend against her culture and she may become an outcast.

The patient's religious views may affect his or her attitude towards medical treatment in other ways. It is important for healthcare providers to be aware of religious, cultural and developmental needs even though it may not be possible, for reasons of fairness to other users of state-funded services, to meet all these.[303] Healthcare professionals also need to be aware of the ways their own beliefs or values may affect the way they approach others. Different religions vary according to the weight given to the four principles of beneficence, non-maleficence, justice and autonomy because their underlying ethos is Christian.[304] The decision making process may vary. The Jewish approach is said to be casuistic, therefore, each case should be considered on its own merits without 'zealous adherence to general principles'.[305] Islam values the principles of beneficence and non-maleficence so the Moslem doctor's oath incorporates these and the principle of justice. Autonomy is a lesser concept[306] so paternalism is accepted because society requires a 'focus on the family rather than the individual'.[307] Serour believes the doctor's duty to save lives and pursue medical knowledge means that advancement of medical technology can be put before patient welfare.[308] The doctor who tries to enhance patient autonomy and exclude the Moslem family may be causing offence. Decisions to withhold or withdraw treatment which will result in certain death are said to be particularly difficult for Moslems because the '(b)eneficence of God can be expected to save the patient until the last minute'.[309] According to Florida, the concept of autonomy is foreign to the Buddhist so decision-making models tend to be paternalistic.[310] However, there is a danger that doctors who rely upon selective accounts such as those given above may inadvertently offend or act in a discriminatory manner because they expect patient or families to act according to the 'label' they have given them.[311]

How cultural views affect a patient's life goals should be respected by the clinician and healthcare purchaser whose own views should be irrelevant, subject only to the proviso that no one should be forced to provide treatment s/he disagrees with.[312] Some patients request 'inappropriate' treatment on religious grounds.[313] Classifying certain treatments, or continuation of active therapy, as 'inappropriate' introduces bias into the decision-making process overly weighting some implied 'norm' at the expense of the genuine belief of the patient or his/her family.[314] Orr and Genesen consider that religious beliefs are more than personal preferences because they represent certain extrinsic values but because they are concerned with the meaning of life they are more 'intrinsic' than other community values.[315] This suggests that strongly-held personal religious beliefs should be given 'serious consideration' by clinicians and the possibility that a certain approach to treatment

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[303]Terry L, Campbell A. *Hearing Children's Voices.* A paper presented at The Third Annual Trevor Clay Memorial Conference, Philosophy in Nursing, 15 September 2000, Middlesex University. See also: Terry L, Campbell A. Hearing Children's Voices: Are We Listening? *British Journal of Nursing* (forthcoming - accepted for publication 27 February 2001).

[304]Raanon Gillon, for his *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester, invited a variety of contributors to explain how their particular religion viewed the four principles.

[305]Steinberg A. 'A Jewish perspective on the Four Principles'. In Gillon R.*Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp65-73 at 66.

[306]Serour GI. 'Islam and the Four Principles'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp75-91 at 80-81 & 86. See also, the approval of the casuistic approach given in *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 at p117F per Walker LJ.

[307]Hasan KZ. 'Islam and the Four Principles: a Pakistani View'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp 93-103 at p97.

[308]Serour GI. 'Islam and the Four Principles'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp75-91 at p87.

[309]Hasan, op cit n307, at p100.

[310]Florida RE. 'Buddhism and the Four Principles'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp105-116 at p111.

[311]Terry & Campbell, op cit n303.

[312]In some cases, English law protects doctors by means of a statutory prohibition on certain types of 'religious' treatment such as female circumcision: The Prohibition on Female Circumcision Act 1985.

[313]Orr RD, Genesen LB. Requests for 'inappropriate' treatment based on religious beliefs. *J.Med.Ethics* 1997;**23**:142-147.

[314]Ibid.

[315]Ibid.

may be appropriate for that individual be accepted.[316]

5.3.1.2 Patients without capacity

With incompetent patients, decisions may be based upon an assessment of their best interests. Underpinning the best interests approach is a balancing of the benefits and burdens of treatment. The principles of beneficence and non-maleficence are more significant when the patient is unable to exercise autonomy. The decision-makers may be the parents/legal guardians of a child, doctors or the judiciary.[317] It has been recognised that 'the decision-maker's impression of that patient's experience...may well be inaccurate'.[318] Thus, the 'best interests' assessment may have no correlation with patient preferences if s/he was able to communicate them. Decision-makers may be guided by what they imagine the patient would feel to be his/her best interests and inadvertently may reflect their own preferences rather than the patient's. The possibility of one person accurately deciding what is in another's best interests when s/he has no knowledge of that individual's subjective experience is merely a convenient fiction. The degree of closeness of the two parties may affect the quality of the assessment. When a parent makes decisions on behalf of a child, the child's life experiences and family goals and preferences are known although the child's subjective interpretation of these experiences and reflective criticism of family preferences may be unknown.[319] So, although 'best interests' focuses on discovering what is 'sufficient' for the incompetent patient, it is important to recognise that such decisions are not neutral. They necessarily involve making a value-laden judgment about another's life which generally means making a quality of life judgment. The decision-maker is rarely unable to avoid projecting onto that judgment his/her own views as to what is an acceptable quality of life.[320] Such views might also incorporate an assessment of the degree of risk to the doctor in adopting one course of action or another. Personal risk assessment may affect whether the doctor concludes a patient is competent.[321]

An alternative to determining the 'best interests' of an individual is to use 'substituted judgment'. This model relies upon the decision-maker asking what preferences would the patient express if able to do so. It has been strongly criticised in light of the conceptual difficulties it raises.[322] Like the 'best interests' model, quality of life issues are heavily weighted. Actual use of both models indicates that 'best interests' and 'substituted judgment' overlap and both are, at times, unsatisfactory compromises.[323]

Some countries allow the appointment of a proxy decision-maker to act in the event of the (adult) patient

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[316]Ibid, at p146. See also: Gillon R. Imposed separation of conjoined twins - moral hubris by the English courts? *J.Med.Ethics* 2001;27:3-4.
[317]See discussion in the next chapter regarding legal issues surrounding decision-making for incompetent patients.
[318]Elliott C, Elliott B. From the patient's point of view: medical ethics and the moral imagination. *J.Med.Ethics* 1991;**17**:173-8 at p176.
[319]It is submitted that even very young children will have made some sort of evaluation as to whether they consider certain family goals/preferences acceptable to them and have some awareness of what feels right for them even though the language of identification and evaluation is still closed to them: Terry & Campbell, op cit n303.
[320]See, for instance: *B (A Minor) (Wardship: Medical Treatment), Re* [1981] 1 WLR 1421.
[321]Wilks I. The debate over risk-related standards of competence. *Bioethics* 1997;**11**,5:413-426 at pp19-24.
[322]See, for instance, Elliott C, Elliott B. From the patient's point of view: medical ethics and the moral imagination. *J.Med.Ethics* 1991;**17**:173-8. Also, Kennedy I, Grubb A. *Medical Law Text and Materials* 3rd Edn 2000 Butterworths, London at pp831-842.
[323]See *Re J (a minor) (wardship:medical treatment)* [1991] Fam 33 and *Superintendent of Belchertown State School v Joseph Saikewicz* Mass 370 NE 2d 417 (1977).

becoming incompetent, temporarily or permanently.[324] In England, this is currently under review.[325] Providing the proxy is 'faithful...to the person's intentions and values'[326] the concept offers advantages over the often ad hoc system whereby clinicians seek to discover what the patient would have wanted by asking the most available or most assertive relative. However, neither advance directives nor proxy decision-makers can force a doctor to provide illegal, futile or inappropriate treatment since incompetent patients cannot be placed in a better position than competent ones.[327] There is a clear distinction between proxy decisions and those made in a patient's 'best interests' or using 'substituted judgment'. The proxy can make the decision as s/he thinks fit, not necessarily in the person's best interests[328] nor by attempting intellectual gymnastics so as to make the decision as the incompetent person would if not incompetent. English law requires decisions to be in the patient's best interests whoever makes them.[329] Sometimes parents seem to act as proxies rather than in their child's 'best interests' particularly where they have the interests of two children to consider.[330] Delaney describes bone-marrow donations by siblings of children with leukaemia as 'altruism by proxy'.[331]

The use of a proxy offers advantages over advance directives since s/he will be able to accommodate advances in medical technology and changes in the patient's views although both are fraught with difficulties. People's views change regarding both treatment and proxy, though these difficulties are avoidable by regular up-dating of the documentation. The uncertain doctor may have to fall back on the 'best interests' model.

5.3.2 The 'Do No Harm' Model

Non-maleficence has ancient roots but is highly relevant today when patients are quick to blame doctors for any outcome differing from the one expected. The 'do no harm' model has four significant strands. One relates to how incompetent patients are to be cared for which has already been discussed. The next relates to iatrogenic illness which is an even greater problem now than when Illich shocked the medical world in 1976.[332] The third relates to the practice of defensive medicine and the last to prohibitions on euthanasia, female circumcision and similar treatments.

Few doctors wish to deliberately harm their patients.[333] Some may negligently harm patients and will be subject

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[324]Proxy decision-makers may also be known as 'surrogate decision-makers' or 'medical attorneys'. The closest English law currently has regarding medical treatment are the (limited) powers given to the 'nearest relative' under the Mental Health Act 1983. However, see discussion of reform proposals later in this thesis.

[325]At present, continuing powers of attorney can be executed allowing control of financial affairs but not medical. In 1988 a Working Party of King's College, London reported on 'living wills' and enduring powers of attorney as means to achieve continued patient autonomy: *The Living Will: Consent to Treatment at the End of Life*. See also: Law Commission Report No 231: Mental Incapacity Law Commission for England and Wales 1995 HMSO, London; Lord Chancellor's Department. *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults.* (Cm 3803) December 1998. The Stationery Office, London and Lord Chancellor's Department. *Making Decisions on Behalf of Mentally Incapacitated Adults.* (Cm 4465) October 1999 The Stationery Office, London.

[326]May WE, McGivney MJ. Making Healthcare Decisions For Others. *Ethics and Medics* 1997;**22**:6.

[327]Law Commission for England and Wales. Report No 231: *Mental Incapacity* 1995 HMSO, London Part V: Advance Statements about Healthcare at p67.

[328]Although English law, as discussed in the next chapter, requires the decision to be made in the patient's 'best interests' a proxy decision-maker theoretically should have the freedom to make the decision just as the patient would and not all decisions people make for themselves are in their best interests.

[329]*Gillick v West Norfolk & Wisbech AHA* [1986] AC 112.

[330]Such decisions are particularly hard in the unusual case of conjoined (Siamese) twins: *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.

[331]Delaney L et al. Altruism by proxy: volunteering children for bone marrow donation. *BMJ* 1996;**312**:240-3.

[332]Illich I. *Limits to Medicine: Medical Nemesis - The Expropriation of Health.* 1976 Penguin, Harmondsworth.

[333]Harold Shipman, convicted of murdering several of his patients, is an exception. *R v Shipman* (2000) unreported. See also: Watson R, Ford R. Murdered patients toll may climb to 345. *The Times* 6 January 2001.

to legal and professional sanctions.[334] Most try hard to avoid harming their patients by being aware of treatment risks and by considering, often with their patients, how these balance against treatment benefits. However, doctors may abuse their powers by excluding patients from discussions about treatment futility.[335] The desire to protect the patient from harm inherent in the doctrine of therapeutic privilege (or 'therapeutic deceit'[336]) may be employed inappropriately. Paternalism may oust autonomy.[337] Confronting the patient with the news of his or her impending death may be seen as destroying hope in some cultures so the patient may be excluded from talks about how death should occur.[338] The assumption that the patient will be harmed by being given unpleasant information is problematic. It requires assessing, often on the basis of limited contact, whether an individual is psychologically robust. The inability to settle 'secular and spiritual' matters may be more harmful.[339]

The problem of iatrogenic illness is beyond the scope of this thesis. It can be seen as evidence not just of dirty and under-resourced hospitals but also as evidence of over-treatment of patients. Treating iatrogenic illnesses is costly.[340]

The practice of defensive medicine is possibly increasing in this country due to fears of litigation.[341] The doctor may continue treatment longer than appropriate because of fears of being sued (or even threats of violence from the patient's family).[342] The development of guidelines by the Royal Colleges provides reassurance in such situations that the doctor has a responsible body of medical opinion supporting him or her.[343] The doctor's fear of being sued may have positive benefits for the patient. The doctor may take extra trouble to ensure s/he has up-to-date information regarding the patient's condition and possible treatment options.[344] S/he may more fully inform the patient when obtaining consent. Thus, defensive practice can be improved practice. Patient autonomy can gain precedence over a more paternalistic approach to care.

Finally, the 'do no harm' model can be seen as underpinning the prohibitions on euthanasia and other controversial treatments. Particularly when the patient is a child, it is important to ensure no harm results. When a child with Down's syndrome has 'corrective' surgery the benefits are said to be better integration into society.[345] However, the child loses his or her own face. This can never be restored and may, in time, be seen as a harm that should never have been allowed to occur. Children who received growth hormone rather than being encouraged to accept shortness of stature and meet the challenges society presents are now dying as a

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[334]See, for example, criticisms of the General Medical Council over its failure to take early disciplinary action against Dr Rodney Ledward and Mr Richard Neale. Marsh B. GMC in dock over second gynaecologist: Another 'butcher' doctor. *Daily Mail* 10 June 2000.

[335]Zucker MB, Zucker HD. *Medical futility and the evaluation of life-sustaining interventions.* 1997 Cambridge University Press, Cambridge at p13.

[336]Tassano F. *The Power of Life or Death: a Critique of Medical Tyranny.* 1995 Duckworth, London at p32.

[337]See, for instance, Muramoto O. Bioethics of the refusal of blood by Jehovah's Witnesses: part 2. A novel approach based on rational non-interventional paternalism. *J.Med.Ethics* 1998;**24:**295-301; Pang M-c.S. Protective truthfulness: the Chinese way of safeguarding patients in informed treatment decisions. *J.Med.Ethics* 1999;**25:**247-253; Rosin AJ, Sonnenblick M. Autonomy and paternalism in geriatric medicine: The Jewish ethical approach to issues of feeding terminally ill patients, and to cardiopulmonary resuscitation. *J.Med.Ethics* 1998;**24:**44-8 and Elger BS and Chevrolet J-C (Commentators). Case Study: Beneficence Today or Autonomy (Maybe) Tomorrow? *Hastings Center Report* 2000;**30,**1:18-19.

[338]Asai A et al. Medical decisions concerning the end of life: a discussion with Japanese physicians. *J.Med.Ethics* 1997;**23**:323-7.

[339]Downie RS, Telfer E. *Caring and Curing: A philosophy of medicine and social work.* 1980 Methuen & Co., Ltd., London at p62.

[340]Hawkes N. Doctors' errors 'cost 40,000 lives a year'. *The Times* 20 December 1999.

[341]Outstanding medical negligence claims allegedly total £2.8 billion. National Audit Office. See also: Our Medical Correspondent. Surgeons 'may drop high-risk patients'. *The Times* 7 September 1999.

[342]Knecht J. 'He is too young to die...and you too, doctor'. *J. Med.Ethics* 1999;**25:**418.

[343]See discussion earlier in this chapter.

[344]The legal issues regarding consent will be discussed in the next chapter.

[345]The fact that the child still has the characteristic shape of head which means that even before the face is seen the child (or adult) can be recognised as having Down's seems irrelevant to the doctors who perform this surgery.

result.[346] Regarding abortion, healthcare professionals can opt out of involvement and a number find the deliberate taking of life, even though it is in the early stages of a pregnancy, to be against their conscience. Euthanasia is seen as murder under English law.[347] However, some argue that to preserve life of intolerable pain is inhumane and a greater harm results through not allowing physician-assisted suicide or euthanasia.[348] Certain treatments are very controversial and can be seen as potentially damaging not only the individual but also wider society.

Lord Devlin was firmly convinced that the law should operate at any time when the 'reasonable man' feels 'disgust' - '(t)he vast majority of people in this country still believe that certain practices are morally wrong and are content that they should be forbidden by the law as such'.[349] However, feeling 'disgust' is not proof of immorality. It could lead to the preferencing of ill-thought, ill-informed responses over educated views. This view would mean that certain procedures should be banned, such as gender reassignment, transgenic transplants and amputations of healthy limbs. Freeman suggests that arguments for taking account of the disgust factor in legislation, as advocated by the Warnock Committee, have been decisively overturned.[350] The law should command public respect but it is difficult for the public to understand why female circumcision is prohibited yet the total removal of external reproductive organs is allowable.

5.3.3 Social Etiquette Models

Some models seemed based on an interpretation of how society works or should work. Consequently, treatment decisions can be made according to general courtesy (respect for others); length of time in the queue ('wait your turn'); whether the patient deserves treatment ('you get what you deserve'/'you've only got what was coming to you') or the rights of individuals within a democracy.

5.3.3.1 Respecting Others

The 'respect for persons' model of decision-making is one of the most important in a multi-cultural society although Campbell's critique reveals the difficulties in the suggestion that 'moral' actions are those which are based upon respect for other persons.[351] Each person has value and should be respected regardless of race, religion, class, age, disability etc.[352] Other's goals and objectives are as valuable as one's own. Consequently, no patient has the right to insist that a doctor carries out treatment s/he opposes.[353] This model also holds that no doctor can force a medical intervention on a patient except in certain, restricted circumstances because the liberty of one should not be interfered with unless it is to prevent a restriction upon the liberty of others and

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[346]The growth hormone was taken from the pituitary gland of newly deceased adults some of whom had been suffering from senile dementia. These children, twenty years on, have now been found in some cases to have developed an early, fatal senility called Creutzfeld Jacob disease (CJD). This is not the variant CJD being found in some young people which is being associated with Bovine Spongiform Encephalitis (mad cow disease).

[347]In America, Dr Jack Kevorkian has recently been convicted of murder. The charge resulted from a video he made of himself injecting three compounds into a patient to cause death. For an interesting documentary which includes this video see: Channel 4 TV *Appointment with Dr Death.* 14 June 1999.

[348]The discussion of euthanasia and physician-assisted suicide is beyond the scope of this thesis.

[349]Devlin P: *The Enforcement of Morals.* 1965 Oxford University Press, London at p125.

[350]The Human Fertilisation and Embryology Act 1990 to a certain extent reflects this view that whatever causes disgust in the reasonable man (or Warnock Committee member) should be legislated against. See: Freeman MDA: *Medicine, Ethics and the Law: Current Legal Problems* 1988 Stevens & Sons, London at p17.

[351]Campbell AV. *Moral Dilemmas in Medicine*. 3rd Edn. 1984 Churchill Livingstone, Edinburgh at pp86-105.

[352]Not, for example, treated simply as cannon fodder for an army the lack of which was one of the principal reasons the state started to take an interest in healthcare in this country.

[353]Although a duty to refer the patient to another doctor may exist.

then it should only be restricted so far as is necessary to ensure all have equal liberty.[354] Where liberty, in terms of freedom to participate fully in society, is restricted through ill-health or disability, the health care system should seek to redress the imbalance. In contrast, utilitarianism permits inequality in health and inequality of treatment because it seeks merely to maximise overall welfare.

Although equal respect is a sound model for healthcare delivery, it is not clear that respect for others is the 'motivating factor behind all doctoring' nor how far respect for others extends.[355] The equal respect model may suggest that patients whose illness is a consequence of smoking should receive equal care as if their illness were not self-induced. The difficulty with this is that the costs of treating avoidable self-induced conditions may unfairly impinge upon the liberty of others to receive treatment bearing in mind the limited resources available. The self-abuser has failed to treat others within society with respect. Whether this should lead to a reduction in care is problematic.[356]

Balanced against the possibility of reducing care is the 'central obligation' of non-abandonment. Quill and Cassel argue that this is an under-emphasised aspect of being a physician.[357] They suggest that it is 'particularly mandated' by two aspects of modern medicine. First, the prevalence of chronic illness where ethics must move beyond short-term decision-making to 'establishing a relationship grounded in continuity, realistic expectations and a shared understanding of goals and values'.[358] Second, the changing healthcare environment and the new emphasis on 'managed care systems' and 'approaches to cost containment'.[359] Quill and Cassel believe that recognition of an obligation of non-abandonment would 'focus attention on the most vulnerable individual persons and groups and would encourage health care professionals to struggle on their behalf'.[360] Quill and Cassel believe non-abandonment is most closely related to the principle of beneficence but it seems more properly conceptualised as respect for others.[361] However, the obligation cannot be accepted as meaning that all that can be done, should be done, which the maxim, 'where there's life, there's hope' suggests.[362] Respect for persons means working together, as doctor and patient, to discover the right treatment decisions. A major difficulty arises with the concept of respect for persons: what is a person/personhood? At what point does personhood which must be respected arise and when is it lost? There is no definitive answer.[363] The principle of autonomy can be seen as a direct derivative of the concept of respect for personhood.[364]

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[354]For instance, in the case of mental illness (a patient sectioned under s3 Mental Health Act 1983 can be treated for their mental illness without consent for the first 3 months) or with certain infectious diseases the patient can be hospitalised and treated under the Public Health (Control of Disease) Act 1984. In some cases, pregnant women have been forced to undergo Caesarean sections against their wishes: *R v St George's Healthcare NHS Trust ex p S* [1998] 2 FLR 728.

[355]Mason & McCall Smith op cit n43 at p7.

[356]See the discussion below regarding 'just deserts' and government strategies outlined by the Secretary of State for Health in *Saving Lives: Our Healthier Nation* (Cm 4386) 1999 The Stationery Office, London.

[357]Quill TE, Cassel CK. Nonabandonment: A Central Obligation for Physicians. *Trends in Health Care, Law and Ethics* 1995;**10**,1-2:25-32.

[358]Ibid, at p25.

[359]Ibid.

[360]Ibid, at p29.

[361]For the same reason I disagree with Pellegrino's suggestion that the only way Quill and Cassel's theory can work is to accept non-abandonment as a principle in its own right, which he argues defeats their thesis. See: Pellegrino ED. Nonabandonment: An Old Obligation Revisited. *Annals of Internal Medicine* 1995;**122**,5:377-8.

[362]'Ita quinquam derelinquatis aegros, semper sperate salutem' (Never give up with a patient, where there's life there's hope): Reilly M: Some Plymouth Worthies (Part 2) 0 *West of England Medical J.* 1990;**105**(ii):48-50 at p50.

[363]These questions arose in *Airedale NHS Trust v Bland* [1993] AC 789 and also in *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.

[364]Robertson DW. Ethical theory, ethnography, and differences between doctors and nurses in approaches to patient care. *J.Med.Ethics* 1996;**22**:292-299.

5.3.3.2 Queuing Time

Individual GPs and consultants can prioritise the patient on basis of need but there will still be a waiting period. Political manipulation of waiting times can lead to problems in service delivery. The admissions system takes little account of patient welfare or ability to benefit. Mason and McCall Smith suggest that the public may prefer this method of allocation.[365] In reality, it is injustice masquerading as justice since the queuing system can be manipulated by knowledgeable patients. The judiciary uphold the lottery model if the alternative means making an order requiring that a particular patient received a certain resource, regardless of other demands for that resource.[366]

Because British hospitals mostly operate a 'turnstile' system, once a patient has been admitted to hospital, if some other aspect of health then deteriorates, treatment is received for that as well as for the admitting cause.[367] Thus, there is a lottery favouring certain people over those whose condition is possibly as serious but who are still awaiting admission.[368] Langford suggests that two criteria exist for deciding who gets a scarce resource: medical prognosis and medical emergency and the latter 'takes precedence'.[369] It should be questioned whether it is right to always give the emergency precedence. Langford suggests that where patients are partly to blame for their condition, under the consideration of medical prognosis, although 'a *past fault* would not be ground for discrimination,...a *present condition*, for example of continuing alcoholism, could be if it rendered medical prognosis poor'.[370] The difficulty is that when a medical emergency occurs, the amount of information available to guide the decision-making process is often limited and so some patients may receive treatment by default.[371]

The queuing system can also be subject to geographical variations.[372] In the U.S.A. the allocation of donor organs has been subject to prioritisation on the basis of need within a local area first, then a regional and finally a national level.[373] This can be seen as 'taking care of one's own'.[374] It is discriminatory, and potentially socially divisive, particularly if 'one's own' prioritised one racial, cultural or ethnic group to the exclusion of others.[375] Geographical preferences can easily become personal preferences which damage society and vice versa.

The NHS Plan introduces maximum waiting time guarantees.[376] Similar guarantees are provided in Norway subject to the individual patient meeting certain criteria rather than the blanket approach proposed in the UK.[377]

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[365]Mason JK, McCall Smith RA. *Law and Medical Ethics* 4th Edn.1994 Butterworths, London at p263.

[366]Ibid, at p264 (discussion of *Re J(a minor)(child in care: medical treatment)* [1993] Fam 15.

[367]Given the extent of iatrogenic illness this is perhaps comforting for patients: Illich I. *Limits to Medicine: Medical Nemesis - The expropriation of health.* 1976 Penguin, Harmondsworth.

[368]This can be particularly galling for clinicians who have patients needing admission but another patient has a crisis, particularly if it was partly self-induced. For instance, as one consultant interviewed related, older people on coach trips may decide not to take their diuretics before travelling in case they need to pass urine before the coach reaches a stopping point. When they develop chest pains as a result and have to be admitted to hospital they take priority over local residents.

[369]Langford MJ. Who gets the kidney machine? *J.Med.Ethics* 1992;**18**:12-17 at p12.

[370]Ibid, at p13 - his emphases.

[371]For instance, there may be insufficient data concerning a patient who has had a cardiac arrest to support a decision not to attempt resuscitation. In such cases the 'rule' is to start resuscitation.

[372]For instance, regarding coronary bypass operations. Department of Health. *Saving Lives: Our Healthier Nation* (Cm 4386) July 1999 The Stationery Office, London para 6.15.

[373]Veatch RM. A New Basis for Allocating Livers for Transplant. *Kennedy Institute of Ethics Journal* 2000;**10:**75-80.

[374]Ibid, at p76.

[375]For example, see the reports of 'racist' conditions being attached to donor organs: McGrory D. Surgeons ignored donor conditions. *The Times* 9 July 1999 (Asians only condition) and Wilkinson P, McGrory D. Union officials leaked racist donor request. *The Times* 8 July 1999 (whites only condition).

[376]NHS Plan: A plan for investment, a plan for reform. (Cm 4818-1) 2000 The Stationery Office, London chapter 12. Available on www.nhs.uk/nhsplan accessed 7 August 2000.

[377]Holm S et al. Access to Health Care in Scandinavian Countries: Ethical Aspects. *Health Care Analysis* 1999;**7:**321-330 at p325

The Norwegian approach seems scientifically more valid and helps reduce GPs and consultants being swamped by 'worried well'.

5.3.3.3 Just Deserts

This model conceptualises healthcare as a reward for acceptable behaviour. This can be based on the behaviour of a community or individual behaviour. In some parts of the U.S.A. hospitals which have actively procured organs for transplantation receive priority for organs.[378] On an individual basis, treatment decisions could be made favouring the 'most deserving' individual but this is a highly subjective determination: is it the mother with four children who smokes or the person with no family who has adopted as healthy a lifestyle as possible? Merit-based protocols have been proposed for Scotland.[379] Social class or talent may be determinative.[380] Dworkin argues talent is luck, not merit deserving tribute.[381] Treatment decisions may be made, possibly unconsciously, by those with the power to withhold resources or influence their allocation, so as to favour 'deserving' patients.[382] This model is likely to become increasingly important as the NHS moves towards the target-based approach to healthcare described in *Saving Lives: Our Healthier Nation.*[383] This details individual contributions towards health.[384] The seeds have been sown for future governments to imply that individuals who have not taken measures to stay healthy have broken their social contract with the country and should not expect to receive treatment.[385]

5.3.3.4 Democratic Rights

Engelhardt believes that there is no 'canonical, content-full secular ethics' discoverable by reflection, therefore, healthcare rights can only be determined by democratic processes.[386] Whether 'democracy' alone can guide medical decision-making is questionable although this may be the ultimate goal of current governmental policy with the introduction of NICE and the National Survey of Patient and User Experience[387] and the increasing emphasis on individual responsibility for health as part of the social contract. Democracies, simply by their existence, recognise the principle of justice. The democratic process necessitates balancing individual rights so no one's rights are paramount. Democratic societies only exist where the members consider it mutually beneficial to co-operate but this does not mean autonomy is unimportant. By recognising any sort of democratic process as a model for decision-making, Engelhardt impliedly validates the four principles. Democratic societies, by their very nature, recognise certain basic rights to healthcare and these rights, rather than being dictated by public agreement alone are premised upon ethical principles and doctrines.

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[378]See Mason & McCall Smith, op cit n43 at p260. First call goes to these hospitals to see if the available organ is suitable for any of their patients and if it is not then it becomes available elsewhere.

[379]Leonard S. Penalty points scheme rations heart surgery. *The Sunday Times* 18 July 1999.

[380]See: Weaver JL. *National health policy: Ethnic Minorities, Women and the Elderly.* 1976 The CV Mosby Company, St Louis at p145 where he relates how several commentators in the 1970s placed the blame for the individual's poverty-related ill-health on the individual's social class thereby absolving 'schools, labor unions, corporate industries, hospitals and similar institutions of responsibility'.

[381]Dworkin R. *Sovereign Virtue: The Theory and Practice of Equality.* 2000 Harvard University Press, London at p325.

[382]Lindbladh E et al. Equity is out of fashion? An essay on autonomy and health policy in the individualized society. *Soc.Sci.Med.* 1998;**46**,8:1017-1025.

[383]*Saving Lives: Our Healthier Nation*, op cit n372.

[384]Ibid, Appendix 1. This sets out 'National Contracts' and lists what individuals can do; what communities can do and what the government can do.

[385]Lindbladh et al suggest this is the Swedish approach already. Lindbladh et al, op cit n382 at p1018.

[386]Engelhardt HT. 'The Four Principles of Healthcare Ethics and Post-Modernity: why a libertarian interpretation is unavoidable'. In Gillon R, *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp135-157 at p137.

[387]Department of Health. *A First Class Service: Quality in the NHS* 1998 The Stationery Office, London.

Stoll considers that a democratic rights model would help address the problem that different doctors may rank the same patient's need for care dissimilarly.[388] Stoll favours multi-disciplinary national committees to develop codes of medical practice so that decisions about whether or how to treat a patient or not could be made in accordance with the views of society and based upon sound principles since '(s)ociety should openly acknowledge the justification for such rationing decisions and approve guidelines for allocating priorities'.[389] However, it is difficult to set aside personal preferences so if a panel member, close friend or relative, has a certain condition that member will often want that condition to receive a high priority for treatment.[390] This is possibly truer of lay or non-professional people although this might be a myth promulgated by the professional classes who wish to maintain power by restricting access to 'outsiders'. The views delivered may reflect the social class and age of members more than the local community.[391]

Individual rights to healthcare have only had weak support to date in this country. The Patients' Charter gave no concrete rights, merely a right to complain.[392] Although the European Social Charter 1961, Article 11, Part 1 spoke of rights 'to enjoy the highest standard of health obtainable' Britain's obligations under Part 2 are merely to 'remove so far as is possible to remove the causes of ill-health' within a framework which encouraged 'individual responsibility'.[393] The individual responsibility model has been increasingly important since 1990. Likewise, the duties of the Secretary of State for Health to 'secure improvement in...the physical and mental health of the people'[394] were diluted by the proviso that any services were simply to be provided as he 'considers necessary'.[395] The freedom of the NHS Trusts to provide treatments they felt patients were entitled to is restricted by a duty to 'achieve such financial objectives as...set by the Secretary of State'.[396]

Rights are not unproblematic. For instance, a 'right to treatment' or a 'right to die' may be claimed by patients or their relatives. Simply asserting a right does not necessarily mean that there is an obligation on society or the individual doctor to meet that demand.[397] MacCormick sees rights as interests which 'ought' to be protected even if others refuse to admit that certain rights exist.[398] The difficulty is in deciding which interests should be protected.[399] Dworkin considers that there are various rights, some of which 'trump' others ie. they take precedence over rights they are in conflict with.[400] Certain individual rights will even, according to Dworkin, trump the general welfare of society and must be protected.[401] However, when the rights of two

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[388]Stoll BA. Choosing between cancer patients. *J.Med Ethics* 1990;**16**:71-74 at p73.His suggestions include greater use of objective guidelines and audit mixed with QALYs.

[389]Ibid, at p73. The role of NICE will be to produce guidelines and national codes of practice.

[390]Lamb D. Priorities in healthcare. Reply to Lewis and Charny. *J.Med.Ethics* 1989;**15**:33-4.

[391]Certainly, with many groups like Community Health Councils, the membership is often drawn from a relatively narrow sector of society. The government has not made it clear how it will ensure that the contributors to the proposed National Survey of Patient and User Experience will be representative of society.

[392]Department of Health. *The Patients' Charter and You: A Charter for England.* 1991 (revised 1995) Dept. of Health, Wetherby.

[393]For a useful summary of these healthcare rights see: McHale J, Fox M and Murphy J. *Health Care Law* 1997 Sweet & Maxwell,London at pp7-9.

[394]National Health Service Act 1977 s1.

[395]National Health Service Act 1977 s3.

[396]National Health Service and Community Care Act 1990 s10.

[397]The 'Tavistock Group' has recently published a code of ethics designed to develop continuity of approach by all healthcare professions which enumerates as one of the 'governing principles' a right to healthcare. Smith R. Shared ethical principles for everybody in health care: a working draft from the Tavistock Group. *BMJ* 1999;**318**:248-251.

[398]MacCormick N. *Legal Rights and Social Democracy.* 1982 Oxford University Press, Oxford.

[399]For example, see the opposite views regarding whether foetuses have rights in Dworkin R. *Life's Dominion.* 1993 Harper Collins, London at p18 and Belshaw C. Abortion, Value and the Sanctity of Life. *Bioethics* 1997;**11**,2:130-150.

[400]Dworkin R. *Taking Rights Seriously* 1977 Duckworth, London. In particular, see Chapter 6 'Justice and Rights' at pp150-183.

[401]Ibid, at p367.

individuals are in conflict, a balancing exercise may be necessary.[402]

The concept of 'parental rights' is particularly problematic. Society feels disquiet when medical treatment is withheld against parental demand. However, parental wishes cannot always be supported at society's expense or contrary to the doctor's beliefs and judgement. As Freeman recognises, 'often parents misuse the rights vested in them by biology' consequently 'parental authority is frequently abusive, harmful and detrimental to the child'.[403] Excessively burdensome treatment could be tantamount to abuse[404] and constitute 'a victimising abandonment of our responsibility to do no harm to patients'.[405] Others believe the ability to develop 'personhood' is the key. Absent this, although 'death is *not* inevitable (such) infants may...lose the right to have their lives prolonged'.[406] However, many severely-handicapped infants have the ability to develop 'personhood' so the debate circles back to 'which lives count?'[407] and whose opinion counts?

Freeman sees 'rights' as prioritising the civil liberties of all which he admits could be costly to the general welfare of society.[408] He suggests that rights can be viewed three ways.[409] Firstly as something which can be trumped by special considerations ('goals of special urgency' eg. war, which trumps the right to strike); secondly as something that trumps all else, even utility and when in conflict with other rights the one promoted is the one that 'maximises the fulfilment of rights' and thirdly, as something that is absolute and can constrain others.[410] Adopting the second view, he argues that the patient's rights should be given paramountcy in the decision-making process over third-party considerations of patient welfare or 'best interests'. Difficulties arise, however, when the patient's rights conflict with national interests or with another patient.[411] In the UK, individual rights seem second to fiscal requirements which suggests that securing a healthy national economy is a 'goal of special urgency' at least as far as the government is concerned. Neither the state nor the NHS sees rights 'as trumps'. If they did, 'it would mean that no cost could be spared in providing health care to all in need of it; it would mean that our rights to education, food, shelter, clothing etc. would have to be compromised in cases of conflict'.[412] Uddo's analysis of U.S. federal policy on forgoing treatment or care suggests that, where the legislature has attempted to introduce rights to non-discrimination on grounds of disability, judicial interpretation weakens or ignores their intent and doctors object to the encroachment on their territory.[413] English courts also follow medical opinion at the expense of individual rights.[414] If a democratic model for medical decision-making is to be adopted, it must be supported by the judiciary and doctors.

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[402]For instance, if an HIV positive patient does not wish his/her partner to be informed, the doctor may reserve the right to inform the partner: Campbell A et al. *Medical Ethics* 2nd Edn. 1997 Oxford University Press, Oxford at pp115-7. Contra, Ainslie DC. Questioning Bioethics: AIDS, Sexual Ethics and the Duty to Warn. *Hastings Center Report* 1999;**29**,5:26-35. See also, *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 - discussion in next chapter.

[403]Freedman M: The Best Interests of the Child? Is *The Best Interests* of the Child in the Best Interests of the Child? *J.Law, Policy and the Family* 1997;11:360-388 at p365

[404]van der Heide A et al. Medical end-of-life decisions made for neonates and infants in the Netherlands. 1997 *The Lancet* **350**:251-5.

[405]Waisel DB, Troug RD. The cardiopulmonary resuscitation-not-indicated order: Futility revisited. *Annals Int.Med.* 1995;**12**,4:304-8 at p306.

[406]Doyal L & Wilsher D. Towards guidelines for withholding and withdrawing of life prolonging treatment in neonatal medicine. *Arch.Dis.Child.*1994;**70**:F66-F70 at F70 (their emphasis).

[407]Belshaw C. Abortion, Value and the Sanctity of Life. *Bioethics* 1997;**11**,2:130-150 at p141.

[408]Freeman MDA. Sterilising the Mentally Handicapped in Freeman MDA. *Medicine, Ethics and the Law: Current Legal Problems* 1988 Stevens & Sons, London at p76.

[409]Ibid, at p77.

[410]Ibid.

[411]See: *Re B (A Minor) (Adoption Order: Nationality)* [1999] 2 WLR 714 and *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.

[412]Bell NK.(Ed) *Who Decides? Conflicts of Rights in Health Care.* 1982 Human Press, Clifton, New Jersey at p16.

[413]Uddo BJ. Federal policy on forgoing treatment or care. *Issues in Law and Medicine* 1992;**8**(3):293-308. See, in particular, the discussion at pp294-300.

[414]See the discussion in the next chapter.

The problem with 'rights' is that this view of ethics sees 'persons as social and moral atoms, actually or potentially in competition with one another'.[415] The Human Rights Act 1998 will be used as a way to assert individual rights to healthcare.[416] Coote suggests that healthcare should seen as 'a right of citizenship, rather than a matter of privilege or luck'.[417] However, a strong rights ethos may be objected to on the grounds that this places individuals before communities. The 1998 Act may strengthen the rights of the learning disabled to receive equal access to treatments such as organ donation.[418] The way delegated power is exercised will be challengeable. Challenges will have to be heard expeditiously and impartially[419] with an effective remedy available.[420] Because human rights can be seen as 'rights individuals have in relation to governments'[421] it is likely that this model sees healthcare rights being seen as firmly linked to responsibilities. *Saving Lives: Our Healthier Nation* adopts this approach.[422]

5.4 Discussion

5.4.1 The weaknesses of politico-economic models

The politico-economic decision-making models are essentially utilitarian. As such they are open to the same objections as the classical theories of Mill[423] and Bentham.[424] Consequently, these models fail to gain societal acceptance because they demand acceptance that some may be denied treatment so others can benefit. Once the human genome is fully mapped a utilitarian healthcare system might use this to prioritise the genetically fortunate.[425] The problem is that welfare is impossible to measure accurately. Models such as QALYs attempt this but the fact that doctors generally do not consider QALYs suggests that strict utilitarianism is considered immoral.

Underlying utilitarianism is a central belief in the rationality of decision-making but rational processes can result in unethical results. Decision are not only pragmatically or prudentially based, but morally based. Utilitarianism does not explain why following a moral course of action, which is possibly contrary to one's personal interests, to maximise total welfare is desirable. Ultimately, patients want what is best for them, not for society.[426] The politico-economic models seek the good of society and consequently no individual has a guaranteed right to all, or any, potentially beneficial treatment.

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[415]Morgan D. Technology and the Political Economy of Reproduction. In: Freeman MDA. *Medicine, Ethics and the Law: Current Legal Problems* 1988 Stevens & Sons, London at p46.

[416]The courts began considering its influence before it came into force: *R v North and East Devon HA, ex parte Coughlan* [2000] 2 WLR 622 and *Re W (Wardship: Discharge: Publicity)* [1995] 2 FLR 466.

[417]Coote A. Is there a crisis in health care? In: Fabian Society *Pamphlet 574 Health Crisis - What Crisis? Proceedings of the Fabian/Socialist Health Association New Year Conference 1996* 1996 pp14-17 at p16.

[418]For an example of discrimination see: Channel 4 TV. *Cutting Edge: A New Heart for Jo.* September 1996. This discusses the case of a girl with Down's syndrome denied the opportunity of a heart transplant.

[419]Article 6(1) European Convention of Human Rights. For an example where the impartiality of the House of Lords is questionable see: *R v Bournewood Community and Mental Health Trust ex parte L* [1999] 1 AC 458.

[420]Article 13 European Convention of Human Rights.

[421]Annas GJ. Human Rights and Health - The Universal Declaration of Human Rights at 50. *NEJM* 1998;**339,**24:1778-1781.

[422]Department of Health. *Saving Lives: Our Healthier Nation* (Cm 4386) 1999 The Stationery Office, London.

[423]Mill JS. *Utilitarianism; On Liberty.* 1871 Williams G (Ed). 1993 JM Dent, London.

[424]Bentham J. *An Introduction to the Principles of Morals and Legislation*. Burns JH, Hart HLA (Eds) 1970 The Althone Press, University of London, London. See also: Hart HLA. *Essays on Bentham* (Nos 7 & 8) 1982 Oxford University Press, Oxford.

[425]See: Cedar S, Terry L. Genes and Genealogy *Family Law* 2000;**30**:744-747 and McLean SAM, Giesen D: Legal and Ethical Considerations of the Human Genome Project. 1994 *Med.Law International* **1**:159-175 at 169-170.

[426]Cobbs LS, Clark PA and Brusa M. The Million Dollar Question: Commentaries. *Hastings Center Report* 2000;**30**,5:24-26.

Doctors see their patients as individuals but politico-economic models ignore the distinctness of persons. The underlying utilitarian ethos means that past promises hold no sway.[427] Therefore, the promises made at the inception of the NHS can be broken in the interests of maximising welfare. This jars against the clinician's traditional belief in a duty of fidelity towards his or her patient. The 1991 reforms removed the traditional freedom of doctors to refer patients to the most appropriate treatment facility. They felt unable to do the best for their patients individually.

An alternative to adopting one goal as the measure of welfare, is that of seeking to discover which goals and objectives are valuable. Then, Simmonds suggests, laws and institutions can maximise the welfare from these preferences.[428] The present political approach to health is muddled. Quantity of lives saved seems to be the measure of welfare not quality.[429] Yet life can be seen as only of value to the individual. Saving someone's life but leaving him/her a 'cardiac cripple'[430] or vegetative is contrary to acceptable medical practice and probably contrary to public expectations. Therefore, it seems that the proper goal of laws and institutions is the maximisation of ability to participate in society. However, the recent consultation exercise carried out by the government suggests it has confused maximising public participation in goal and objective setting with maximising individual participation by reducing the barriers erected by ill-health and disability.[431]

Rawls' powerful critique of utilitarianism proposes a 'social contract' grounded on two principles.[432] The difference principle holds that social and economic differences are only allowable providing they work to the advantage of those least well-off in society. The RAWP formula was designed to rectify regional underfunding but, in order to do so within the finances available, better-funded areas would have had to experience cutbacks. Rather than even out matters quickly a gradual phasing-in was used and inequity remains. Thus political expediency leads to the prolonged continuation of an unjust situation. However, Dworkin's analysis of Rawls's theory suggests that this was inevitable since the difference principle 'attends...only to those who have fewest primary goods...no matter what the consequences for those who will still have more'.[433] Gillon argues that the Rawlsian deliberators would 'require at least a reasonable *chance* that any meetable health care need will be met' and that 'if they were to be seriously ill their doctors and nurses should maintain their care and concern and palliation'.[434] This argument reflects public opinion. Yet, as Williams asserts '(n)o society can afford to offer all its members all the health care that might possibly do them some good.'[435] *Saving Lives* builds upon the notion of social contracts and the obligations of individuals towards society but the long-term threat potentially is that those who break their 'contracts' do not deserve care.[436]

Another difficulty Rawls fails to address is that the 'social primary goods' revealed may differ from society to society.[437] Some may consider that any inequality in distribution at all is unjust even if it is designed to even out inequalities. The rhetoric about the National Plan for the NHS suggests that both equality of access and

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[427]Simmonds NE. *Central Issues in Jurisprudence: Justice, Law and Rights.* 1986 Sweet & Maxwell, London at p19. *R v North and East Devon HA, ex parte Coughlan* [2000] 2 WLR 622 is an exception.
[428]Ibid, at p27.
[429]*Saving Lives: Our Healthier Nation*, op cit n372.
[430]Someone whose quality of life, following a major cardiac arrest and the consequent damage to heart muscle, is greatly diminished.
[431]Department of Health. *Creating a 21st century NHS.* 2000 Internet site: www.nhs.uk/nationalplan accessed 5 June 2000.
[432]Rawls J. *A Theory of Justice.*1972. Oxford University Press, Oxford.
[433]Dworkin R. *Sovereign Virtue: The Theory and Practice of Equality.* 2000 Harvard University Press, London at p331.
[434]Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp797-806 at p799.
[435]Williams A. 'Economics, Society and Health Care Ethics'. In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp829-842 at p829.
[436]Department of Health. *Saving Lives: Our Healthier Nation* July 1999 The Stationery Office, London.
[437]These include liberty, self-respect, opportunity and wealth.

equality of outcome are the aims and there is a failure to realise that both are not achievable in a resource-limited service. Ultimately, politico-economic models rely upon the public accepting theories of distribution which they little understand.

5.4.2 The weaknesses of medical models

The most obvious failure of medical models of decision-making is that there is great potential for paternalism[438] to creep in which directly conflicts with the concept of autonomy or respect for persons. However, there is a fine line between respecting a patient's right to act autonomously by giving him/her the knowledge to make his/her own decision, and forcing knowledge upon him/her that harms.[439] To move from 'the destructiveness of complete lies to the destructiveness of unmediated truth'[440] is undesirable but the alternative often seems to be that patient preferences are ignored on the grounds that the doctor, with his/her expertise 'knows' what is medically, ethically or socially correct. Tassano points out that paternalistically protecting patients from choices the doctor considers wrong can result in great harm.[441] The imbalance in clinical knowledge leads to an power imbalance between doctor and patient although patients are becoming more knowledgeable through the media and the internet. Although patients may lack the skill to interpret this data accurately they increasingly challenge medical expertise and authority. Doctors are afraid of becoming the means by which all patient preferences are to be satisfied.[442] Maintaining the power imbalance through devices like guidelines helps avoid this.

5.4.3 The weaknesses of ethical models

Regarding the right to self-determination, it is unclear, certainly regarding healthcare, whether people can accurately assess what will maximise personal happiness. Preferences may alter with knowledge or experience.[443] Not all patient preferences can be met by state-funded systems so ways to determine the legitimacy of different preferences become necessary. Some people would have their preferences met and others would not so the system becomes inherently inequitable. Certain personal preferences are objectionable to society and would need controlling to protect the rights of others.[444] There is also a danger that unrealistic expectations are raised. The model implies that patients expressing a desire for treatment should receive it regardless of predicted outcome.[445]

The 'do no harm' models can mistakenly distinguish between causing harm and failing to prevent harm from happening. Feinberg believes both are equally blameworthy because people have moral rights based upon them having certain interests such as life.[446] However, Feinberg tries to limit the extent of rights, and corresponding duties in others. Duties to assist can only be indeterminate when more people need to be assisted than there

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[438]The paternalistic medical model can be seen as based upon Aristotle's description of 'unequal friendship'. Aristotle *The Nicomachean Ethics* (Translated by Ross, D.) 1925 World Classics, Oxford University Press, Oxford at pp203-205 *(Ethics* VIII 7).
[439]Cassell EJ. The Principles of the Belmont Report Revisited. *Hastings Center Report* 2000;**30**,4:12-21.
[440]Ibid, at p17.
[441]Tassano F. *The Power of Life or Death: a Critique of Medical Tyranny.* 1995 Duckworth, London at p69.
[442]Ibid, at p47.
[443]For example, many patients, once they have been given accurate information as to the success rates of resuscitation attempts, or who have had one resuscitation attempt made on them, then express a desire to have resuscitation withheld in future: Murphy DJ et al. The influence of the probability of survival on patients' preferences regarding resuscitation. *NEJM* 1994;**330:**545-9.
[444]For example, racist restrictions attached to donated organs for transplantation.
[445]For example, *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.
[446]This is known as the 'Interest' principle. Feinberg J. *Rights, Justice and the Bounds of Liberty.* 1980 Princetown University Press, Princetown, USA.

are resources to aid them.[447] Menlove accepts that, otherwise, the duty would give rise to a correlative right[448] but is unconvinced by the justifications Feinberg gives for limiting the existence of a duty to rescue.[449] The Patients' Charter inadvertently developed a 'rights' culture in healthcare leading to tension when the predominantly utilitarian NHS failed to deliver.

The most obvious weakness of the ethical models is that to work successfully the underpinning ethical principles need to be recognised and an appropriate way found to balance them when they are in conflict with each other.[450] Although principles like beneficence, non-maleficence, autonomy and justice are valuable, they can mean different things to different people.[451] As Gillon asserts, each has relevance and acceptability regardless of the religious (or cultural) viewpoint adopted.[452] However, whether they can serve as a decision-making model is debatable.[453] This was never their primary purpose. Their greatest value is that they have provided a common language for the critique of decision-making processes and theories of distribution rather than providing a new theory of ethics.[454] Some suggest that the additional principles of respect for the sanctity of life and honesty are required but Gillon, probably correctly, dismisses these and other proposed principles of respect for law, liberty and rights as aspects of respect for persons.[455]

Gillon asserts that the expression of the four principles will produce 'a better-reasoned, more critical approach to personal and moral decision making, better awareness of opposing moral positions and...moral positions opposed to one's own, and an awareness that there are some moral values...subscribed to by all, or most'.[456] However, as shown earlier, doctors rarely take a principled approach to decision-making and prefer to rely upon 'experience'. They may use the principles afterwards in justification like a flakjacket. Ethics assumes 'alternative options are often open' in the healthcare arena when in reality they are non-existent.[457]

When choosing between two or more patients, each of whom should receive treatment, but it is only possible to treat one, the four principles alone are of little assistance. Similarly, when deciding what treatments should be funded by the NHS the four principles fail to produce consensus. The justice principle, in particular, is capable of multiple constructions. Justice to a market economist may mean sacrificing the older, economically non-productive patient but to a rights campaigner, justice may mean equal opportunity to benefit regardless of age.

5.5 The Reality of Decision-Making

Klein et al have identified seven forms of rationing. There is rationing by denial; selection; deflection;

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[447]Feinberg J. *The Moral Limits of the Criminal Law Vol 1: Harm to Others*. 1984 Oxford University Press, New York at p144.
[448]Menlove MA, McCall Smith A, *The Philosophical Foundations of a Duty to Rescue*. In Menlove MA & McCall Smith A: *The Duty to Rescue*. 1993 Dartmouth Publishing Co Ltd, Aldershot at pp4-50 at p19.
[449]Ibid, at p20.
[450]For an example of the difficulty balancing ethical principles and doctrines, see: *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.
[451]See: Gillon R. *Principles of Health Care Ethics* 1985 John Wiley & Son, Chichester at p323.
[452]Ibid, at p320.
[453]Attempts have been made such as the model described by Malley PB, Reilly EP. *Legal and Ethical Dimensions for Mental Health Professionals*. 1999 Accelerated Development, Philadelphia at pp30-31.
[454]Botros S. 'Rights and the Four Principles' in Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester at pp231-240.
[455]Gillon, op cit n451 at pp328 -9.
[456]Ibid, at pp326.
[457]Raphael DD. *Moral Philosophy* 2nd Edn. 1994 Oxford University Press, Oxford at p114.

deterrence; delay; dilution and by termination.[458] The reality is that all of the models described above are ways of rationing the level of treatment given. Politico-economic models are more open about rationing than medical or ethical models although all try to avoid the word.[459] All models are subject to manipulation by the decision-maker. As shown, all of the models described above are used at different times by doctors. The model used depends upon the surrounding circumstances such as whether the consultant feels pressurised by the family to continue treatment, or whether the consultant believes the patient's stated preference is one that should be met.

Doctors jealously guard their 'clinical freedom...to act in the best interests of the...patient as perceived by both the doctor and the patient'.[460] Politicians considered doctors took 'insufficient account of opportunity costs and the need for society as a whole...to determine how the money available should be spent'[461] so this freedom was curtailed by the 1991 reforms. Care must be 'cost-effective'. The question that governments tend to ask is 'which patients are...selected for treatment?' not which treatment to give a patient.[462] Yet patients 'want to be accepted without question or qualification' and to receive 'the best treatment for themselves, not the best treatment for the providers, nor the patient body as a whole, nor for society'.[463] Harris believes the choices offered should not be influenced by costs to others or whether others could benefit more. Equality of access and opportunity are paramount then it is 'up to the patient herself to choose whether or not to forego her own chance of treatment, either in her own interests or in the interests of others or society'.[464] Harris fails to recognise society's legitimate interest in the allocation of societal resources. Justice in distribution is important, but it may be appropriate to limit treatment options without necessarily creating 'an aristocracy of the fortunate'.[465] Patients are understandably reluctant to deny themselves potentially beneficial treatment so the state must impose some restrictions if it is paying. The decision-making process can be improved by debating ways of enabling society to be realistic in its demands on pooled resources and possibly encouraging individual altruism.[466] Since decisions to withhold or withdraw treatment are more commonly made by patients' relatives, following medical advice, than by the patient, this may be more achievable than immediately apparent.[467] Currently, the medical profession accepts as legitimate the relatives' role,[468] possibly because patients are poor at refusing treatment, although '(g)uilt and denial may compel relatives to press for aggressive treatment'.[469] Lindgren recognises family involvement as appropriate, because 'the surviving family has the biggest stake in the decision over a dying, unconscious patient (so) whatever pain or welfare will be enhanced by a particular decision will be borne particularly by the family'.[470] Public opinion polls show greatest support for families and doctors making non-treatment decisions together rather than families alone with the courts being 'little trusted'.[471] However, recent exposure of medical malpractice and murder in Britain means that many elderly patients are losing trust in their physicians. Their fears could be addressed by ensuring better

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[458]Klein, Day & Redmayne, op cit n91, at pp11-12.
[459]Ibid, at p66.
[460]Chantler C et al. Translating good ideas into appropriate action. In: Hopkins (Ed). *Appropriate investigation and treatment in clinical practice* 1989 Royal College of Physicians of London, London at p97.
[461]Ibid, at p98.
[462]Harris J. What is the good of health care? *Bioethics* 1996;**10**,4:269-291 at 271.
[463]Ibid, at p272.
[464]Ibid, at p277.
[465]Ibid, at p279.
[466]Harris recognises that 'no one is entitled to have their own needs met whatever the cost'. Harris , op cit n462, at p290.
[467]Wilson AC et al. Ordering and Administration of Sedatives and Analgesics During the Withholding and Withdrawal of Life Support From Critically Ill Patients. *JAMA* 1992;**267**,7:949-953.
[468]The legal status of relatives will be examined in in the next chapter.
[469]Kipnis K & Gerhard A. Some Ethical Principles for Adult Critical Care. *Hawaii Med.J.* 1995,**54**:482-5 at 484.
[470]Lindgren J. Death by Default. *Law and Contemporary Problems.* 1993;**56**,3:185-259 at 225.
[471]Ibid, at 225-7.

recognition of their rights to treatment.

Since healthcare is about 'the provision of information and...decision making'[472] it seems clear that any suggestions for improving the decision-making process will need to support patient autonomy. Doctors have the clinical knowledge and the scientific skills to analyse outcomes data so as to present the patient with a prognosis.[473] Many patients are 'more ignorant about health care than...other commodities'[474] and some 'welcome the opportunity to pass difficult decision-making to the doctor'.[475] However, disagreement exists as to whether all treatment decisions should be made by joint consultation between doctor and patient. van Delden opposes the Dutch approach whereby, if the physician deems the treatment 'futile', the non-treatment decision is solely the physician's responsibility.[476] van Delden believes patients should 'have the opportunity to evaluate' even those conditions which, if treated, necessitate 'constant monitoring, ventilatory support and intensive care nursing'.[477] However, Davies points out that patients usually assume there must be some benefit so opt for treatment.[478] Bruce-Jones suggests that 'direct patient involvement in health decisions is necessary if "quality of life" is invoked' even though guidelines imposing a prima facie duty to canvass patient opinion are liked less by doctors than patients.[479] There is some evidence that treatments which twenty years ago were considered uncommon have now become so 'routine' that doctors fail to initiate discussions about whether to withhold or withdraw them.[480] If the patient is competent, only s/he should assess her/his quality of life otherwise third party assessment of quality of life is legitimated.[481] Any suggestions for improving the decision-making process will need to address the reluctance of some doctors to involve patients to the extent that the individual patient wishes.

Giving strong support to patient autonomy is not the same as allowing patient preference to become dominant. Most doctors (and courts[482]) consider that doctors are not obliged to provide treatment failing to offer at least 'a modicum of clinical benefit'.[483] However, the power imbalance between the doctor and the patient can lead to one being able to 'exploit' the other without the reverse necessarily being true. For example, treatment may be provided 'against the professional intuition of the physician',[484] and against the patient's wishes because doctors fear litigation or because of gender issues.[485] This offends the adage 'above all, do no harm'. Gillon, discussing the moral difference between killing and letting die, says, ' a doctor who imposes life-prolonging treatment on a patient who competently rejects it is clearly failing to respect the patient's autonomy, (but) a doctor who refuses a patient request to be killed does *not* infringe the patient's autonomy'.[486] Wreen suggests that what he calls the 'operative principle' should be employed in cases where there is 'a question as to the

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[472]Mooney G. QALYs: are they enough? A health economist's perspective. *J.Med.Ethics* 1989;**15**:148-152 at 151.
[473]However, Gilligan points out that 'treatment decisions are influenced not only by outcome probabilities but also by the physician's personal values and priorities': Gilligan T. Whose death is it anyway? *Ann.Int.Med.* 1996;**125**,2:137-141 at 139.
[474]Mooney, op cit n472, at p152.
[475]Ibid, at p152.
[476]van Delden JJM et al. Deciding not to resuscitate in Dutch hospitals. *J.Med.Ethics* 1993;**19**:200-205 at p204.
[477]Ibid.
[478]Davies JM & Reynolds BM. The ethics of cardiopulmonary resuscitation. 1 Background to decision making. *Arch.Dis.Child.* 1992;**67**:1498-1501 at 1499.
[479]Bruce-Jones PNE. Resuscitation decisions in the elderly: a discussion of current thinking. *J.Med.Ethics* 1996;**22**:286-291 at p288.
[480]Pijnenborg L et al: Withdrawal or Withholding of Treatment at the End of Life. *Arch.Int.Med.*1995;**155**:286-292 at 290.
[481]McCormick RA. To save or to let die. *JAMA* 1974;**229:**174. See also the discussion in Bayles M, High DM (Eds). Medical Treatment of the Dying: Moral Issues. 1978 GK Hall & Co. Shenkman Publishers, Cambridge, Massachusetts at p91.
[482]As will be shown in the next chapter.
[483]Brett AS & McCullagh LB. When patients request specific interventions. *NEJM* 1986;**315**:1347-1351.
[484]Pijnenborg et al, op cit n480, at p291.
[485]Gilligan T. Whose death is it anyway? *Ann.Int.Med.* 1996;**125**,2:137-141, at p139.
[486]Gillon R. Euthanasia, withholding life-prolonging treatment, and moral differences between killing and letting die. *J.Med.Ethics* 1988;**14**:115-7 at 116.

validity of the patient's decision' so that 'we ought to err on the side of his best interests'.[487] In reply, who is able to decide the patient's 'best interests' if not the patient? If the patient is competent, autonomy must be protected. Wreen's argument that autonomy should not be protected so far as to let the patient refuse life-saving treatment since if autonomy is 'isolated from other values, an autonomous patient might refuse treatment for utterly trivial...reasons'[488] is flawed because he ignores the enforced Caesarian section cases.[489] However, many doctors seem to agree and consider genuinely-held views 'trivial' or 'bizarre'.[490] Where the patient's views are grounded on cultural or religious preferences trivialising them is racist and discriminatory.

Some non-treatment decisions will result in the death of the patient. Deciding who has a chance to live or not is sometimes decided 'by balancing the familial and social costs/benefits'.[491] Is it appropriate to withhold treatment just because the family costs are too high? This means requiring the most vulnerable to act as 'sacrificial lambs' and amounts to imposing a duty on them to 'rescue' others in preference to themselves. This must be untenable although it is generally accepted that if society has limited resources not all can receive treatment.

5.6 Conclusion

Sound treatment decisions can only be made when it is recognised that medical ethics is not solely about doctor-patient relationships. Social policy and political ideology, influenced by lobbyists, affect resource allocation.[492] More openness is needed by those involved in the resource allocation process. The NHS is manipulated for political gains, but disguising the problems of limited resources and/or reduced commitment to the welfare state with measures to increase public 'choice' or 'say' treats the public as simpletons. It does grave disservice to clinicians who try to achieve the best for individual patients. The passing of power to unelected managers was 'not only harmful to patients, but also massively wasteful'.[493] Limits to what any country can spend on healthcare have to be acknowledged but this is a matter for informed public debate not political gesturing. Through the Primary Care Groups, the public is being involved in the process of determining what treatments and for whom the NHS should provide. However, public contribution has to be based on better understanding of healthcare than presently seems evident. Consultation exercises should be robust in construction so the opinions gained have value.[494] Geographical differences in healthcare provision should be as unacceptable as differences based on gender, race, social importance or ability/disability. Doctors should not be viewed with suspicion or treated as political scapegoats.[495] Their contribution to the debate is vitally important as possessors, and imparters, of medical information. Decisions should not be based solely

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[487]Wreen MJ. Autonomy, religious values and refusal of life-saving medical treatment. *J.Med.Ethics* 1991;**17:**124-130 at p125.
[488]Ibid, at p126.
[489]Ibid, at p125.
[490]Fortunately, for believers in rational people's freedom to make 'irrational' decisions, the Court of Appeal has not agreed with Wreen: *R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728.
[491]Long TA. Infanticide for handicapped infants: sometimes it's a metaphysical dispute. *J.Med.Ethics* 1988;**14:**79-81,80. See also: Kuhse H, Singer P. *Should the baby live: the problem of handicapped infants.* 1985 Oxford University Press, Oxford and Ramsey P. *Ethics at the edges of life*. 1978 Yale Univ. Press, New Haven.
[492]Campbell AV. *Nonesuch* (University of Bristol Magazine) Autumn 1996 pp 27-29.
[493]Black D. Paying for health. *J.Med.Ethics* 1991;**17:**117-123, 123.
[494]The recent Department of Health consultation exercise 'Have your say on a better NHS' conducted in June 2000 can be criticised for its lack of research robustness. There were delays over sending out the printed leaflets which meant the date by which responses were to be received (5 June 2000) had to be changed. The leaflets only appear to have been produced in English which meant that many users of the NHS (for example, ethnic minorities; people with poor literacy skills; sight-impaired and learning disabled) were excluded from the consultation exercise. Department of Health. *Creating a 21st century NHS.* 2000 Internet site: www.nhs.uk/nationalplan accessed 5 June 2000.
[495]As, for example, by Tony Blair in a recent interview: Miles, A. Can the NHS be Saved?: Last Chance *The Times* 26 May 2000.

on finances. Cost-effectiveness is only part of the debate which needs to address the potential efficacy of treatment.

As Dowie asserts, the goal of medical decision-making is to '*make the best decision in an individual case*, not to be "ethically correct" - or "technically correct"...in some abstract or general sense'.[496] Certainly, absolute 'correctness' is impossible in a highly subjective and evolving field like medicine but the 'best' decisions aim to be as ethically and technically 'sound' as possible. Decisions command respect when premised upon sound reasoning and principles. Historically, the medical model was predominant with little consideration given to patient-preferences. As clinicians become more enlightened, and patients less compliant, patient preference has gained more importance although support for patient autonomy depends very much upon the individuals concerned - doctor, patient and possibly family.

Moves to control expenditure led to the development of economic models but the criticisms of these have produced new combinations which attempt to marry cost and clinical effectiveness. The model currently promoted by the government is an evidence-based model which signifies that medical values (good science) are important as long as they are coupled with a cost-effectiveness model for more equitable national delivery. The previous government made the mistake of challenging doctors head-on by trying to place treatment costs before treatment outcomes. The new approach aims to exploit the weaknesses inherent in the medical professions avowed dedication to scientific values. Much medical 'evidence' is little more than 'experience' and 'clinical intuition'. Hence, the government's emphasis on evidence-based medicine has the sub-text that if the 'evidence' is not conclusive, treatment should be withheld. That seems to be the role of NICE which flies in the face of the BMA's belief that medical audit must be 'totally independent of the state'.[497] The present government seems to hope for unquestioning acceptance of its resource allocation strategy at national level through the adoption of these measures. However, national solutions are not necessarily the most equitable way of handling local problems. The marriage of science, economics and politics is unlikely to be happy. The medical models were obviously preferred by the consultant interviewees but many decisions seemed to be based on the 'Blue Peter' model of reasoning whereby, providing there were no complaints or problems with a preceding case, the next similar one is handled the same way.[498] A concerted effort needs making to discover what constitutes a medically and socially robust healthcare decision. Until then, government controls will continue to fret both doctors and patients. Society demands more of government than merely balancing books and spinning soundbites. Therefore, the debate about which treatments should be given and which treatments withheld or withdrawn must seek to find ways to develop a just and justifiable model for making decisions about individual patients not just 'the people'.[499] It is clear that the scientific model is important and good science relies upon openness about what treatment options are possibly available. Similarly, the democratic process requires openness and transparency about resource allocation decisions. It will also be necessary to decide who should be involved in the decision-making process and the extent to which patient preferences should be met. Respect for autonomy is central to both ethical decision-making and the democratic process but individual interests will have to be balanced against societal interests in a proportionate manner.

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[496]Dowie J. 'Decision Analysis: the Ethical Approach to Medical Decision-Making' In Gillon R. *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp421-434 at p421. His emphasis.
[497]Rivett G. *From Cradle to Grave: Fifty years of the NHS.* 1998 Kings Fund, London at p213.
[498]The 'Blue Peter' BBC television programme is familiar to many. As the presenters demonstrated how to make an object, finished versions would be produced with the words, 'here's one I did earlier'.
[499]Department of Health. *A First Class Service: Quality in the NHS* 1998 The Stationery Office, London at para 2.3.

CHAPTER SIX

DECISION-MAKING IN NON-TREATMENT CASES BY THE JUDICIARY

The previous chapter examined how political-economists, doctors and ethicists suggest individual patient decisions should be made. This chapter examines how the judiciary make such decisions and what guidance is provided for future cases. Good medical decision-making is said to reflect a balance of the principles: beneficence, non-maleficence, autonomy and justice.[1] Legal decision-making is bound by rules of interpretation and precedent. The courts may be asked to resolve conflict over non-treatment decisions. At other times, the courts are involved because previous case law holds it is necessary to seek a declaration regarding lawfulness.[2] Although Weir states that the 'legal right of autonomous patients to refuse medical treatment is undeniable'[3] this right may be challenged when the welfare of a third party is involved.[4] Also, society, through law, limits physician power.[5] A tension has arisen as a result of medical advances straining the boundaries of ethical conduct and the public purse. Whether the courts are the best forum and whether their decision-making capacity is better than the medical profession's, or more representative of societal views (if these should be considered), is questionable. The case law falls into two categories: (1) the doctor proposes actively treating; (2) the doctor proposes not treating. Some challenges are because inadequacy of resources bars treatment others are because of patient or family opposition to the doctor's proposal.

6.1 Doctor is Pro-treatment

6.1.1. Lack of Societal Resources Bars Treatment

A House of Lords Select Committee concluded that 'treatment limiting decisions should never be influenced by resource availability' - a doctor's concern should be for the individual patient immediately before him, not what the hospital or society can afford since these decisions should be made 'elsewhere than in the hospital ward or the doctor's consulting room'.[6] In *ex parte Fisher*, it was held that 'when deciding whether to prescribe treatment to a patient a clinician has to have regard to many factors, including the resources available for that treatment and the needs of and likely benefit to that patient, as compared to other patients'.[7] Likewise,

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[1]See: Gillon R. *Principles of Health Care Ethics.* 1994 John Wiley & Sons, Chichester, and Beauchamp TL, Childress JF. *Principles of Biomedical Ethics* 4th Edn. 1994 Oxford University Press, Oxford.

[2]As explained in *R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728 at pp754-5 an application for declaratory relief is the 'usual procedure when a health authority has taken the initiative in seeking the court's ruling on lawfulness of treatment' (or withholding/withdrawing treatment) whereas an application for an injunction is the 'usual procedure when it is the patient who is taking the initiative'.

[3]Weir RF. *Abating Treatment with Critically Ill Patients: Ethical and Legal Limits to the Medical Prolongation of Life*. 1989 Oxford University Press, New York at pp39.

[4]For example *R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728.

[5]For instance, not just in legislation controlling issues such as abortion, but also in the changes to the structure of the NHS found in the Acts of 1990 and 1999 (see Chapter 2).

[6]The House of Lords Select Committee on Medical Ethics *Report of the Select Committee on Medical Ethics* HL Paper 21 (1994) HMSO, London at p376.

[7]*R v North Derbyshire HA ex parte Fisher* [1997] 8 Med LR 327 at p337. For a comment see: Dyer C. Ruling on interferon beta will hit all health authorities. *BMJ* 1997;**315:**146. See also: *R v Secretary of State for Health, ex parte Pfizer Ltd* QBD 26 May 1999, TLR 17 June 1999.

'the severity of a condition may have to be matched against the availability of resources'.[8] However, the courts will be slow to interpret statutory duties as discretions.[9]

In *Knight*, inadequate care allegedly led to a patient's suicide.[10] Facilities were 'grossly and comprehensively inadequate',[11] but the court had to remember that 'the allocation of resources is a matter for Parliament' so the prison service was not negligent.[12] However, imprisoned pregnant women are entitled to the same obstetric care as if at liberty, suggesting that although the unborn child is not a legal person, its existence secures greater protection for the mother.[13] This implies that the 'oneness' rejected in *St George's*, where a pregnant woman's refusal of a life-saving Caesarian section was upheld, has validity.[14]

People may use judicial review to coerce doctors or health authorities into providing medical treatment thereby prioritising the applicant over other patients.[15] 'One day' the courts may address social policy in resource allocation but the judiciary generally avoid this.[16] The courts are not 'arbiters as to the merits of cases of this kind. Were we to express opinions as to the likelihood of the effectiveness of medical treatment, or as to the merits of medical judgment, then we should be straying far from the sphere which under our constitution is accorded to us. We have one function only, which is to rule upon the lawfulness of decisions'.[17] However, in *Bournewood* the House of Lords regrettably deferred to the government's financial arguments.[18] This suggests that future courts may consider not just ethical arguments but economic ones when deciding the lawfulness of non-treatment decisions. Health authority decisions will not be overturned unless they are *Wednesbury*-unreasonable[19] which indicates that policy trumps 'best interests'.[20] The decision in *Fisher* was only quashed because NHS Executive guidance was interpreted as a directive so the decision not to fund treatment was improperly made.[21] Trusts are not allowed to overspend.[22] *Fox* suggests that lack of resources may be a valid reason for a health authority not to give treatment so application for judicial review could be refused.[23] It is unnecessary for public bodies exercising discretion to reveal how they reached their decision.[24] However, 'blanket bans' may be held unlawful.[25] As previously shown, some doctors adopt the role of 'agent' in balancing hospital or healthcare purchaser needs against patient need. *Hincks* confirmed that the Secretary of State has discretionary powers and is not under a duty to ensure Parliament funds all treatment[26] although

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[8] *R v Gloucesterchire CC, ex. p. Barry* [1997] 2 All ER 1 at pp16-17 per Lord Clyde. Dissenting judgments were delivered by Lords Lloyd and Slynn.

[9] *R v East Sussex CC, ex parte Tandy* [1998] AC 714.

[10] *Knight v Home Office* [1990] 3 All ER 237. The NHS is not the only state institution which provides medical care although this thesis has focused on the NHS and the decision-making processes within it.

[11] Ibid, at p241.

[12] Ibid, at p243.

[13] *Brooks v Home Office* [1999] 2 FLR 33.

[14] *R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728.

[15] The number of applications for judicial review in general increased from 491 in 1980 to 3,901 in 1996 but few involve medical treatment decisions: Woolf H. Judicial Review. *LQR* 1998; **114**:579-593,587.

[16] *Bull & Another v Devon HA* [1993] 4 Med LR 117, at p141 per Mustill LJ.

[17] *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055, at p1071 per Bingham MR.

[18] *R v Bournewood Community and Mental Health Trust ex parte L* [1999] 1 AC 458.

[19] *Associated Picture Houses v Wednesbury* [1948] 1 KB 123.

[20] The limitations of the *Wednesbury* principles mean that very few challenges are successful. For example, see: *R v Central Birmingham HA ex parte Walker* (1987) 3 BMLR 32 and *R v Central Birmingham HA ex parte Collier* CA 6 January 1988 (unreported).

[21] *R v North Derbyshire HA ex parte Fisher* [1997] 8 Med LR 327, in particular, see p328 where it is explained that one of the purposes of the NHS Executive in sending out Circular (EL(95)97) was to enable the identification of patients from whom it would be appropriate to withdraw treatment.

[22] NHS and Community Care Act 1990 s10(1).

[23] *R v Ealing District HA, ex parte Fox* [1993] 3 All ER 170. A case where a patient remained in Broadmoor Secure Hospital because suitable care could not be provided in the community.

[24] *R v Higher Education Funding Council* [1994] 1 All ER 651.

[25] *R v North West Lancashire HA ex parte A, D & G.* [2000] WLR 977.

[26] *R v Secretary of State for Social Services, ex parte Hincks* (1980) BMLR 93.

his discretion is not unlimited.[27] The Acts of 1990 and 1999 have not extended his obligations. By analogy with 'the GCHQ' case, it is for the executive, not the courts, to decide whether the requirements of the national budget outweighed fairness to the individual.[28] The courts will not usually intervene in the case of bona fide exercises of statutory discretion.[29] *Ex parte A* held that public authorities must '(1) accurately...assess the nature and seriousness of each type of illness; (2) ...determine the effectiveness of various forms of treatment for it; and (3)...give proper effect to that assessment and that determination in the formulation and individual application of policy'.[30] However, the courts, anticipating the Human Rights Act 1998 coming into force, are critical of budgetary constraints causing mentally ill patients to be detained unnecessarily.[31] Mental Health Act reform proposals suggest a 'principle of reciprocity' so 'where society imposes an obligation on an individual to comply with a programme of treatment and care it should impose a parallel obligation on the health and social care authorities to provide appropriate services'.[32]

Leave is required in order to gain judicial review of a decision[33] but can be refused on the grounds that the decision is not justiciable[34] or no arguable case.[35] Judicial review is really 'too blunt a tool' for 'sensitive' healthcare decisions.[36] The court's powers are limited and, although judges may be tempted out of 'sympathy' to make the order requested, this would be a 'cruel deception'.[37] Individual need has been unsuccessfully argued as the 'only criterion' to be considered, with the provider's lack of resources being irrelevant.[38] Public bodies have a duty to treat fairly all service users[39] but clinical diagnosis/prognosis can make similar patients seem very dissimilar.[40] The publicity may result in treatment becoming accessible via alternative sources.[41] Promises, though, may be enforceable.[42] Fights over which public body holds responsibility waste money better spent on care.[43]

Actions in negligence similarly fail since 'it is settled law that the elements of foreseeability and proximity as well as considerations of fairness, justice and reasonableness are relevant to all cases whatever the nature of the harm sustained'.[44] Public policy militates against finding public bodies negligent in such cases even where

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[27] *Padfield and Others v Minister of Agriculture, Fisheries and Food and Others* [1968] AC 997.

[28] *Council of Civil Service Unions and others v Minister for the Civil Service* [1985] 1 AC 374 at p402. See also Woolf H. Judicial Review. *LQR* 1998; **114**:579-593 at p590.

[29] *Anns v Merton London Borough Council* [1978] AC 728, at p753 per Lord Wilberforce. See also *X (minors) v Bedfordshire CC* [1995] 2 AC 633 (particularly per Lord Browne-Wilkinson) and *Stovin v Wise and Norfolk CC* [1996] AC 923. See also: Feldthusen B. Failure to confer discretionary public benefits: the case for complete negligence immunity. *Tort Law Review* March 1997 pp17-32 and Harris M. Powers into Duties - A small breach in the East Suffolk Wall? *LQR* 1997;**113**:398-403.

[30] *R v North West Lancashire HA ex parte A, D & G.* [2000] WLR 977, at p992 per Auld LJ.

[31] See, for example, *LM v Essex County Council* [1999] 1 FLR 988. See also: *R v London Borough of Sutton, ex parte Tucker* (1998) 40 BMLR 137 where lack of community resources to put into place a care package meant a patient with learning disabilities was unnecessarily detained in hospital.

[32] Mental Health Act Review Expert Group *Draft Outline Proposals* April 1999 The Stationery Office, London at para 19.

[33] Order 53, RSC (SI 1977, No 1955); Supreme Court Act 1981, s31. The claim for judicial review must be brought within three months of the allegedly wrongful decision. This period can be extended in exceptional circumstances if the court considers a grave injustice would otherwise occur.

[34] For instance *R, v Central Birmingham HA, ex parte Walker* (1987) 3 BMLR 32.

[35] Applications for judicial review of decisions by South Lancashire, East Lancashire, Bury and Rochdale Health Authorities not to fund genetically-engineered factor VIII for 4 haemophiliac children were refused on the grounds that the children had not established a right to be considered as special cases: *British Medical Journal* 1997; **314**:695.

[36] *Rv Portsmouth NHS Trust ex parte Glass* [1999] 2 FLR 905, at p908 per Lord Woolf MR.

[37] *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055, at p1074 per Lord Bingham MR.

[38] *R v Gloucestershire CC, ex parte Mahfood; R v Islington, ex parte McMillan. The Times*, June 21, 1995.

[39] *R v Bristol Corporation, ex parte Hendy* [1974] 1 All ER 1047 and *Stovin v Wise and Norfolk CC* [1996] AC 923.

[40] See, for example, the medical estimations regarding treatment success in *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.

[41] See, for instance, *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055 and *R v North West Thames RHA ex parte Daniels* [1994] 109 BMLR 67.

[42] *R v North and East Devon HA, ex parte Coughlan* [2000] 2 WLR 622.

[43] See, for example, *Avon County Council v Hooper and Another* [1997] 1 All ER 532.

[44] *Marc Rich & Co v Bishop Rock Marine* [1995] 3 All ER 307 at p326 per Lord Steyn.

foreseeability and proximity are establishable.[45] However, when targets are set by government, the courts may hold that failure to meet them resulting in harm is negligent.[46]

6.1.2 Patient Refuses Treatment

6.1.2.1 Refusal of Treatment by Competent Patients

Can the patient's wish to have certain treatments withheld, or to discontinue existing treatment, be overturned? The principle of autonomy is reflected in the fact that English law, like others[47], holds it 'a criminal and tortious assault' to treat a patient without consent.[48] Lord Scarman believed it is a 'sound and reasonable proposition that the doctor should be required to exercise care in respecting the patient's right of decision'.[49] He approved the four propositions[50] that (1) every human being of adult years and sound mind has a right to determine what is done with his own body, (2) consent is the informed exercise of a choice entailing a chance to evaluate the options and attendant risks, (3) all 'material' risks should be disclosed by the doctor bearing in mind what the 'prudent patient' would want to know and (4) a doctor may exercise 'therapeutic privilege' and withhold information if disclosure of that information would present a 'serious threat of psychological detriment to the patient'.[51]

St George's, which held a pregnant woman had the right to refuse a life-saving Caesarian section, indicates a strengthening of the view that autonomy should be supported even though treatment was both economically and medically indicated.[52] Brazier and Bridge note that there is no clear definition as to what the courts consider constitutes autonomous choice.[53] They approves Harris' suggestion that choices are autonomous providing they are not defective in reasoning, information, control or stability.[54] It is still uncertain how binding advance refusals of medical treatment will be. In *Bland*, Lord Goff stated that 'it is established that the principle of self-determination requires that respect must be given to the wishes of the patient, so that if an adult patient of sound mind, refuses, however unreasonably, to consent to treatment or care by which his life would or might be prolonged, the doctors responsible for his care must give effect to his wishes'.[55] Lord Mustill spoke of the '(p)aramountcy of the patient's choice'.[56] Providing the competent patient has clearly indicated his/her wishes it would be unlawful to continue treatment.[57] If the patient's refusal seems involuntary, or no longer reflects his/her wishes[58], the court may be asked to overrule it.[59] Some patients may

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[45] *X (minors) v Bedfordshire CC* [1995] AC 633. See also, *Roy v Kensington and Chelsea and Westminster Family Practitioner Committee* [1992] 1 All ER where it was held that rights based on public law could not form the basis of private law actions.
[46] *Kent v Griffiths* [2000] 2 WLR 1158.
[47] See, for example, *Malette v Shulman* (1990) 67 DLR (4th) 321 (Ontario CA).
[48] *Re MB (Medical Treatment)* [1997] 2 FLR 426, at p432 per Butler-Sloss LJ.
[49] *Sidaway v Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital* [1985] AC 871 at p885 per Lord Scarman. His approach is more patient-centred than that of the other four Law Lords whose pro-doctor stance has been strongly criticised: Jones MA. Informed Consent and Other Fairy Stories. *Medical Law Review* 1999;7,2:103-134; Skegg PDG. English Medical Law and 'Informed Consent': An Antipodean Assessment and Alternative. *Medical Law Review* 1999;7,2:135-165.
[50] Given in *Canterbury v Spence*(1972) 464 F 2d 772.
[51] *Sidaway v Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital* [1985] AC 871 at p887.
[52] *R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728. See also, Bailey-Harris R. Comment: St George's Healthcare NHS Trust v S. *Fam Law* 1998;**28:**527 and Bailey-Harris R. 'Patient Autonomy - A Turn in the Tide?' In Freeman M, Lewis A (Eds) *Law and Medicine: Current Legal Issues* Vol 3. 2000 Oxford University Press, Oxford pp127-140.
[53] Brazier M, Bridge C. Coercion or caring: analysing adolescent autonomy. *Legal Studies* 1996;**16:**84-109 at p91.
[54] Ibid, at pp91-93.
[55] *Airedale NHS Trust v Bland* [1993] AC 789 at p864C.
[56] Ibid, at p891H.
[57] *Re AK (Medical Treatment: Consent)* [2001] 1 FLR 129.
[58] Ibid.
[59] In *B v Croydon HA*. [1995] 1 FLR 470 involuntariness seems equated with a lack of capacity.

welcome court intervention but this should not be assumed.[60] If the barrier to acting voluntarily is medical,[61] or religious,[62] this may be treated as evidence of incapacity.[63] It is a dangerous message to send to doctors that incapacity can be determined according to how freely the patient seems able to act. Patients' decisions may be affected by other factors such as perceived obligations to others[64] or religious obligations to accept treatment.[65] Whether the court could then justify overriding these decisions is debatable. Sommerville suggests that to be binding, oral refusals of treatment should be subjected to the same test that was applied in *Re C*[66] with the modification that the patient believed the future illness/condition might befall him/her.[67] The revised *St George's* guidance goes further by recommending that 'unequivocal assurances...in writing' that the consequences of refusal are understood be obtained from the patient.[68] An unacknowledged paradox exists in that the courts indicate that advance directives may be acceptable indicators of patients' wishes provided they are clear yet, unscrutinised, doctors are daily relying upon unprovable assertions by relatives, who have no legal status in the decision-making process regarding adult patients. It may not always be appropriate to recognise advance directives but there is a fine line between protecting patients who would wish their advance directive to be ignored and allowing paternalism full sway.[69]

Thomas J considered that decisions about withholding or withdrawing medical treatment are 'best determined by the application of common principles of humanity and commonsense. These principles are not outside the law but nor are they the prerogative of the law'.[70] Wear and Brahams suggest that 'commonsense morality' should inform the decision-making process regarding treatment refusals.[71] Since it is not 'commonsense' for patients to refuse, or be allowed to refuse, Caesarian sections, the patient's competence is suspect. The rationality of the refusal may be grounds for questioning the patient's competence. The principle of autonomy requires acceptance that a competent patient, with full understanding of his/her decision, is entitled to act 'irrationally'.[72] However, some argue that 'being autonomous requires that a person hold rational beliefs' despite the 'great emphasis on physicians respecting patient autonomy...(which)...encourages tolerance even towards the harmful choices patients make on the basis of their own values'.[73] This 'tolerance' is seen as mistaken and representing 'abandonment' of the patient. This argument, principally directed against Jehovah's Witnesses, assumes that anyone whose choice seems irrational to the scientific mind, must either be ignorant of 'truth',[74] uncaring, or lacking analytical skills so doctors have a 'more extensive' duty to educate patients than previously thought.[75] 'Faith' differs from logic and adherents of any religion may be highly educated and

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[60]Smith DH, Veatch RM (Eds). *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying. A Report by the Hastings Center.* 1987 The Hastings Center, Indiana University Press, Bloomington and Indiapolis at p54.

[61]*Re R (A Minor)(Wardship: Consent to Treatment)* [1992] Fam 11 and *B v Croydon HA.* [1995] 1 FLR 470.

[62]*Re E (A Minor)(Wardship: Medical Treatment)* [1993] 1 FLR 386 and *Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810.

[63]*B v Croydon HA.* [1995] 1 FLR 470 at p475 per Hoffman LJ.

[64]Hardwig J. Is there a duty to die? *Hastings Center Report* 1997;**27,**2:34-42.

[65]Lord Walton of Detchant. Dilemmas of life and death: Part One. *J.Roy.Soc.Med.*1995;**88**:311-5 at p314.

[66]*Re C (Adult: Refusal of Treatment)* [1994] 1 FLR 31. In other words, the patient comprehended and retained the information given regarding his/her illness/condition, believed it and was able to weigh it in the balance.

[67]Sommerville A. Rememberance of conversations past: oral advance statements about medical treatment. *BMJ* 1995; **310:**1663-5 at p1664.

[68]*R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728 and, see also, *Family Law* 1998;**28:**642-4.

[69]For some of the arguments see: Hope T. Advance Directives. *J.Med.Ethics* 1996;**22:**67-8; Ryan CJ. Betting your life: an argument against certain advance directives. *J.Med.Ethics* 1996;**22:**95-9; Luttrell S, Sommerville A. Limiting risks by curtailing rights: a response to Dr Ryan. *J.Med.Ethics* 1996;**22:**100-4 and Savalescu J. Rationalism and Medical Decision-Making. *Bioethics* 1997;**11,**2:115-129.

[70]*Auckland Health Board v Attorney General of New Zealand.* (1993) 1 NZLR 235 at p247. See also: Stauch M. Rationality and the refusal of medical treatment: a critique of the recent approaches of the English courts. *J.Med. Ethics* 1995;**21:**162-165.

[71]Wear AN, Brahams D. At the coalface: to treat or not to treat: the legal, ethical and therapeutic considerations of treatment refusal. *J.Med.Ethics* 1991;**17:**131-135 at p132.

[72]*Re MB (Medical Treatment)* [1997] 2 FLR 426 at pp436-7 per Butler-Sloss LJ.

[73]Savulescu J, Momeyer RW. Should informed consent be based on rational beliefs? *J.Med.Ethics* 1997;**23:**282-8 at 282.

[74]For instance, of the 'correct interpretation' of the bible regarding blood.

[75]Savulescu & Momeyer, op cit n73 at p287.

scholarly. Physicians who attempted 'educating' their patients would undoubtedly lay themselves open to charges of arrogance, intolerance, intrusiveness and unbridled paternalism. Respecting patient autonomy means respecting genuinely-held beliefs not dismissing them.[76] A tendency to examine whether Catholic teachings were being correctly interpreted can be detected in *Re A (Conjoined Twins)* although the court stressed parental opposition was not 'prompted by scruple or dogma'.[77] Doctors should avoid interfering with areas of religious belief although judicial intervention may be appropriate if the patient is not of 'sound mind'.[78] If 'commonsense' is to underpin treatment decisions, it needs consistent interpretation and application - otherwise, it is mere rhetoric utilised to validate the favouring of medical opinion.

In *Re C*, where man with paranoid schizophrenia was refusing a life-saving amputation, Thorpe J held that competence requires (1) being capable of comprehending and retaining the information given; (2) believing the information and (3) being capable of weighing it in the balance to make a decision.[79] In his case, amputation was medically indicated but, economically, his early death was possibly preferable. Although the Court of Appeal in *Re MB*[80] approved this test a departure from objective assessment appeared in the guidelines issued in *St George's*.[81] These indicate that the decision regarding capacity is to be made by the patient's general practitioner or other responsible doctor but 'in serious or complex cases' the issue should be decided by an independent psychiatrist.[82] Therefore, it appears the test in *Re C* may simply be a test for the courts to judge whether the decision arrived at was justifiable. In contrast, the U.S.A. has a rebuttable presumption of capacity which requires four cognitive conditions: 'the ability to comprehend the information relevant to the situation at hand, the ability to appreciate the situation and the consequences of alternative approaches, the ability to weigh the information rationally in the context of a coherent set of goals or values, and the ability to communicate choices regarding care'.[83] Emotional capacity could also be held a requisite for decisional competence so the patient who seems 'indifferent'[84] could be held incompetent.[85]

Patients may be coerced (forced even) into accepting treatment.[86] Anecdotal evidence exists showing that pregnant woman who would prefer to refuse Caesarian sections are frightened, 'in their best interests' into consenting by the threat of legal action.[87] Similar concerns exist regarding the treatment of mentally ill

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[76]See also the discussion of *Application of the President and Directors of Georgetown College Inc.* 331 F2d 1000 (1964) in Kennedy I, Grubb A. *Medical Law: Text and Materials* 2nd Edn 1994 Butterworths, London at pp371-372.

[77]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 at p52D per Ward LJ. A draft judgment was issued on the internet as *Re A (Children)* Case No: B1/2000/2969 Court of Appeal 22 September 2000 www.courtservice.gov.uk.

[78]Stauch M. Rationality and the refusal of medical treatment: a critique of the recent approach of the English courts. *J. Med. Ethics* 1995; **21:**161-6.

[79]*Re C (Adult: Refusal of Medical Treatment)* [1994] 1 FLR 31. Note the similarities to the competencies discussed in Wear AN, Brahams D. At the coalface: to treat or not to treat: the legal, ethical and therapeutic considerations of treatment refusal. *J.Med.Ethics* 1991;**17:**131-135 at 134.

[80]*Re MB (Medical Treatment)* [1997] 2 FLR 426.

[81]*R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728.

[82]Ibid. See also the Comment by Gillian Douglas: November 1998 *Family Law* 1998;**28:**662-4.

[83]Morrison RS et al. When too much is too little. *NEJM* 1996;**335**,23:1755-1759 at p1757. The latter category includes patients who have complete understanding but are unable to communicate their wishes.

[84]*R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728 at p751.

[85]Charland LC. Appreciation and Emotion: Theoretical Reflections on the MacArthur Treatment Competence Study. *Kennedy Institute of Ethics Journal* 1998;**8,**4:359-376. For a commentary see: Applebaum PS. Ought We to Require Emotional Capacity as Part of Decisional Competence. *Kennedy Institute of Ethics Journal* 1998;**8,**4:377-387.

[86]For instance, a patient with mental health illness can be forcibly treated under the Mental Health Act 1983 and certain 'notifiable' diseases such as cholera and tuberculosis render the patient subject to compulsory treatment under the Public Health (Control of Disease) Act 1984 (See list of diseases in Sch.1 Public Health (Infectious Diseases) Regulations 1988. See also: Morrison RS et al. When too much is too little. *NEJM* 1996;**335**,23:1755-1759.

[87]The Association for Improvements in the Maternity Services is a lobby group which is aiming to change the culture that leads to such abuses: Frasier L. Mother sues hospital for 'assault' during childbirth. *Mail on Sunday* 12 April 1998. One law firm which represents 70 NHS Trusts set up a 24 hour telephone helpline for Trusts 'seeking to compel non-compliant women to undergo obstetric intervention' in response to NHS 'need': Hewson B. A woman's freedom under attack. *The Times* 8 July 1997. See also, Mueller MJ et al. Thin on the details: letters and response. *Hastings Center Report* 1997;**27,**1:2-3.

patients[88] and whether women acting as surrogate mothers or tissue donors for a relative have been coerced by family pressure.[89] Such coercion may remain undetected because the Human Fertilisation and Embryology Act 1990 merely requires the 'opportunity to receive suitable counselling'.[90] In *St George's*, the patient was sectioned even though doctors did not intend to provide treatment for mental illness because they wished to protect her unborn child.[91] The American cases of Saikewicz [92] and *Farrell*[93] hold that patient refusal of treatment is subject to the state's interest in preserving life, preventing suicide, safeguarding the integrity of the medical profession and the protection of innocent third parties. American courts may differ according to whether treatment is curative or merely delaying death and quality is preferenced over length.[94] If the outcome is a good quality of life as opposed to a 'wretched' one[95] the state's interest in preserving life and preventing suicide may prevail over patient refusal.[96] The English case of *Robb* suggests patient self-determination overrides such national interests.[97] It is lawful for prison authorities not to enforce treatment.[98] Consequently, the right to refuse treatment or food usually prevails except in a few cases where, rather than appealing to 'state interests' the person's competence is questioned.[99] Savalescu suggests utilising a model of Rawlsian reasonableness whereby 'reasonableness' in rational deliberation requires: use of inductive logic; disposition towards finding reasons for, and against, the proposed solution; being open-minded and making a conscientious attempt to overcome personal prejudices.[100] Regarding failed suicides, withholding care may be viewed as colluding in suicide not as respecting autonomy.

Sometimes the court's finding of competence seems related to how valuable the person is to society. In *Re C* the delusional Broadmoor patient's refusal of life-saving amputation was upheld.[101] The patient in *Re JT* had learning disabilities so, like *Re C*[102], was an economic burden on society.[103] She had tried, then refused, dialysis for her renal failure.[104] She was found competent so the doctor was 'not only entitled to withhold treatment, he (was) bound to respect the patient's wishes'.[105] The court's failure to question why she was not prioritised

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[88]*R v Bournewood Community and Mental Health Trust ex parte L* [1999] 1 AC 458.
[89]Brazier M (Chair). *'Surrogacy: Review for Health Ministers of Current Arrangements for Payments and Regulation - Report of the Review Team'* (The Brazier Report) October 1998 The Stationery Office, London.
[90]Human Fertilisation and Embryology Act 1990 s13(6).
[91]*R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728.
[92]*Superintendent of Belchertown State School v Saikewicz* 373 Mass.728,370 NE 2d 417 (1977).
[93]*In the Matter of Kathleen Farrell*, 529 A 2d 404 (1987) at 410. For a discussion see: MacKay RD. Terminating life-sustaining treatment - recent US developments. *J.Med.Ethics* 1988;**14**:135-139.
[94]In *Bouvia v Superior Court* 225 Cal.Rptr 297 (1986) the court held that the quality of her life was more important than extending it for a possible 15-20 years by artificial nutrition.
[95]*Satz v Permutter* 362 So.2d 160,162 (Fla.Dist.Ct.App.1978). See also: Weir, op cit n3 at p94.
[96]Some American doctors began moving towards the English position about 10 years ago though this may not be reflected in the judicial decisions. For the changing medical approach, see: (1) Principles and Guidelines Concerning the Foregoing of Life-Sustaining Treatment for Adult Patients. *LACMA Physician* 21 Feb. 1986:21 (publication of the Committee on Biomedical Ethics of the Los Angeles County Bar Association and the Los Angeles County Medical Association, (2) Council on Ethical and Judicial Affairs, *Current Opinion of the Council on Ethical and Judicial Affairs of the American Medical Association* 1986 AMA, Chicago, (3) The Hastings Center, *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying.* 1987 Indiana University Pres, Bloomington. For a discussion of the USA judiciary's approach, see: Flamme A, Forster H. 'Legal Limits: When does Autonomy in Health Care Pevail?' In Freeman M, Lewis A (Eds) *Law and Medicine: Current Legal Issues* Vol 3. 2000 Oxford University Press, Oxford pp141-157.
[97]*Home Secretary v Robb* [1995] 1 FLR 412.
[98]Ibid. The reasoning in *Airedale NHS Trust v Bland* [1993] AC 789 was followed, distinguishing *Leigh v Gladstone and Others* (1909) 26 TLR 139 which had been decided at a time when suicide was unlawful. However, in *X v Federal Republic of Germany*, the European Commission on Human Rights held that Article 3 of the European Convention was not contravened by a German law which allowed the force feeding of prisoners on hunger strike since Article 2 obliged the German government to 'secure to everyone the right to life' (N 10565/83 7 EHRR 152, 153).
[99]*B v Croydon HA.* [1995] 1 FLR 470.
[100]Savalescu J. Rationalism and Medical Decision-Making. *Bioethics* 1997;**11**,2:115-129 at pp124-5.
[101]*Re C (Refusal of Medical Treatment)* [1994] 1 FLR 31.
[102]Ibid.
[103]*Re JT (Adult: Refusal of Medical Treatment)* [1998] 1 FLR 48.
[104]Ibid.
[105]Ibid, at p52 per Wall J.

for transplantation, unlike the 'normal' girl in *Re M,* reinforces the idea that some lives have lesser value.[106] In *Rodas*, the paranoid and depressed patient had made a 'rational and reasonable' decision to have his gastronomy tube removed.[107] *Candura* was an elderly lady of fluctuating mental lucidity refusing further 'life-saving' amputation.[108] In *Thor,* it was held that the right of self-determination prevailed.[109] As a quadriplegic he was particularly problematic for the prison services to care for. Issues of patient merit were raised in *Re A (Conjoined Twins)* where Ward LJ was regrettably silent regarding concerns that 'the parents are Kosovan refugees unjustifiably draining our resources'.[110] He could have asserted that, in humanitarian cases, nationality is irrelevant. Although he later stated that the 'indispensible foundation of justice is the basic equality in worth of every human being',[111] the message the courts send out is that the lives of the criminally insane, drug abusers, the disabled, the old and refugees are not worth saving.

The court's findings regarding competence may seem influenced by external factors such as desire not to allow criminals to escape punishment.[112] In *Myers*, following kidney transplantation, the court granted advance authorization of continued treatment because of the state interest in 'upholding orderly prison administration' following concerns that he might use threats to stop his anti-rejection drugs as a way to control his environment.[113] In *Re Caulk,* the healthy prisoner decided to starve himself to death rather than remain in prison and it was held that the balance of state interests went against his right of self-determination.[114] Brady likewise tried to 'control his environment' but the same result was achieved based on his 'incompetence' and 'best interests'.[115] Enforced treatment of notorious criminals may be authorised in order to continue to use them as examples for others. A similar rationale possibly underlies the Caesarean section cases. When treatment is enforced the male-dominated courts broadcast a message that 'virtuous' women do not jeopardise the lives of their unborn children. Similarly, some American decisions suggest that good parents do not abandon their children[116] although refusal may be allowed if the child will not be left destitute.[117] Involving the courts pressurises patients who may feel that they are 'behaving badly' and 'will be punished' because that is the perceived role of the judicial system.[118]

Death may soon follow a decision to refuse treatment, for instance non-resuscitation.[119] Death is more gradual in the case of refusing artificial ventilation, artificial nutrition, dialysis, chemotherapy or antibiotics, giving time for reflection and reversal of the decision. Every day that the patient lives without requesting that treatment is one day more in which s/he reaffirms refusal. Repeated requests for unwanted treatment to stop

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[106]The patient in *Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097 received a new heart within a week although hearts are scarcer than kidneys. JT's family had apparently been screened for compatibility as live donors but none was said to be suitable. Non-suitability is used as a way to protect reluctant 'volunteers' from having to face the condemnation of their families.

[107]*In re Rodas*, No 86PR139 (Colo.Dist.Ct.Mesa County, January 22 1987).

[108]*Lane v Candura* 6 Mass.App.Ct. 377,376 NE 2d 1232 (1976).

[109]*Thor v Superior Court* 885 P 2d 375 (1993).

[110]*Re A (Conjoined Twins: Medical Treatment)* op cit n77, at p8A.

[111]Ibid, at p44C per Ward LJ.

[112]*R v Collins, ex parte Brady* [2000] Lloyd's Rep Med 355.

[113]*Commissioner of Corrections v Myers* 399 NE 2d 452 (1979) at p457. See also, Weir, op cit n3 at pp77-9.

[114]*Re Caulk* 480 A2d 93 (1984). Discussed in *Home Secretary v Robb* [1995] 1 FLR 412.

[115]*Ex parte Brady*, op cit n112.

[116]*Application of the President and Directors of Georgetown College, Inc.*, 331 F2d 1000 (1964). See also the Hastings Center guidelines (*Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying.* 1987 Indiana University Pres, Bloomington) at p55.

[117]*In re Osborne* 294 A 2d 372 (DC App 1972). For a discussion of the anomalies, see Weir, op cit n3 at pp75-7.

[118]For instance, the patient in *Re MB (Medical Treatment)* [1997] 2 FLR 426 'consented' and did not fight against the anaesthetist once the court order had been made: Mason JK, McCall Smith RA, Laurie GT. *Law and Medical Ethics* 5th Edn. 1999 Butterworths, London at p139. This could have been evidence either that she had been attention-seeking before or she was petrified as to what the court would do to her if she did resist.

[119]Hayward M. Cardiopulmonary Resuscitation: are practitioners being realistic? *British J. of Nursing* 1999;**8**,12:810-813.

can also be seen as affirming patient wishes.[120] However, Szasz believes that if the 'collectivist model of healthcare rests squarely on social consensus...it is incompatible with a concept of a right to refuse treatment...(since)...(i)f every individual's good health is an asset to the group, and every individual's ill health is not only a burden but a danger to it, a right to refuse treatment is tantamount to a right to endanger and injure the other members of the community'.[121] Puxton believes that the courts should not consider societal interests since *Re F*[122] held it was not for the judiciary to extend the law this way.[123] Weir supports 'the right of privacy (which) includes a right to die with which the State should not interfere where there are no minor or unborn children and no "clear and present danger to public health, welfare or morals"'.[124] English law is reluctant to recognise a right to privacy[125] although the Human Rights Act 1998 may strengthen such rights.[126]

6.1.3 Patient is Incompetent

St George's holds that competent patients can refuse treatment.[127] The court has jurisdiction regarding children,[128] but *Re F*[129] confirmed that the parens patriae power of the state regarding incompetent adults no longer existed following the revocation of the Royal Warrant in 1960.[130] Its absence was regretted in *Bland*[131]and *T v T.*[132] Dame Elizabeth Butler-Sloss P is critical of the failure of Parliament to legislate in this area.[133] The House of Lords addressed this lacuna by holding that the doctrine of necessity allows doctors can carry out treatment which they deem to be in the patient's 'best interests'.[134] *Bland*[135] confirmed the use of the 'best interests' test.[136] Lord Goff held that doctors should act in accordance with a 'responsible and competent body of relevant professional opinion on the principles set down in *Bolam*[137] ...(and)...it is good practice for doctors to consult relatives'.[138] The proposed act or omission can be declared not unlawful.[139] This country favours the 'best interests' approach for both adults,[140] and children,[141] whereas American courts favour a

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[120]See, for instance, *Bouvia v Superior Court* 225 Cal.Rptr 297 (1986) at p306.

[121]Szasz T. 'The right to refuse treatment.' In: Bell NK (Ed). *Who decides? Conflicts of Rights in Healthcare.* 1982 Humana Press, Clifton, New Jersey. at p114.

[122]*Re F (In Utero)(Wardship)* [1988] Fam 122.

[123]Ibid, at p144 per Balcombe LJ and *Re MB (Medical Treatment)* [1997] 2 FLR 426 at p444, per Butler-Sloss LJ. See also: Puxton M. *Comment on Re MB* [1997] 8 Med LR 228.

[124]Weir, op cit n3 at p91-3 quoting from *In Re Maida Yetter* 62 PaD & C 2d 619 (1973). Weir explains this is not a constitutional right but can be 'traced back' to *Union Pacific Railway Co v Botsford* 141 US 250, 11 S.Ct. 1000 (1891) and is examined in *Roe v Wade* 410 US 113, 93 S.Ct 705 (1973).

[125]See *Airedale NHS Trust v Bland* [1993] AC 789 at pp848-9 for a discussion of this issue.

[126]Article 8.

[127]*R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728.

[128]*Re W (a minor) (medical treatment)* [1993] Fam 64. However, unborn children are not legal persons: *Paton v British Pregnancy Advisory Service Trustees* [1979] 1 QB 276; *C v S* [1987] 1 All ER 1230; *Kelly v Kelly* [1997] 2 FLR 828 and *R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728.

[129]*Re F (mental patient: sterilisation)* [1990] 2 AC 1.

[130]Ibid, at p51E-G per Lord Bridge and pp54H-55B per Lord Brandon. Statutory powers relating to medical treatment exist under the Mental Health Act 1983 but being sectioned under the MHA 1983 is not conclusive of incompetence: see *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 FLR 31 and *R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728.

[131]*Airedale NHS Trust v Bland* [1993] AC 789 at p862 per Lord Goff; at p875 per Lord Lowry and at p883 per Lord Browne-Wilkinson.

[132]*T v T and another* [1988] 1 FLR 400 at p405 per Ward J.

[133]*Re F (Adult: Court's jurisdiction)* [2000] 2 FLR 512 at pp523A-154E.

[134]*Re F (mental patient: sterilisation)* [1990] 2 AC 1. See also, Wilson and Smith's criticism of the failure to consider protecting her from sexual abuse: Wilson W, Smith KLM. The Doctors' Dilemma: Necessity and the Legality of Medical Intervention. *Medical Law International* 1995;1:387-410 at p402.

[135]*Airedale NHS Trust v Bland* [1993] AC 789.

[136]*Re F (mental patient: sterilisation)* [1990] 2 AC 1. See also: Law Commission. *Medical Treatment and Research.* Consultation paper No 129. HMSO, London, para 7.7.

[137]*Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

[138]*Airedale NHS Trust v Bland* [1993] AC 789, 870 per Lord Goff. A further 'gloss' has been added by *Bolitho v City & Hackney Health Authority* [1998] AC 232.

[139]*Airedale NHS Trust v Bland* [1993] AC 789. The declaration is an equitable remedy available under R.S.C., Ord. 15, r16.

[140]*Airedale NHS Trust v Bland* [1993] AC 789.

[141]S1(1) Children Act 1989. A statutory equivalent for adults has been proposed: *Making Decisions* (Cm 4465) October 1999, The Stationery Office, London (discussed in the next chapter).

'substituted judgement' approach.[142] Doctors must consider whether the patient has 'a capacity...commensurate with the gravity of the decision which he purported to make. The more serious the decision, the greater the capacity required. If the patient has the requisite capacity, doctors are bound by his decision. If not, they are free to treat him in what they believe to be his best interests'.[143]

The Royal Colleges are encouraged to articulate their professional opinion in guidelines. The courts accept these without close examination.[144] Lord Mustill's concerns about the 'application of the principle of civil liability in negligence...to decisions on "best interests" in a field dominated by the criminal law'[145] were realised in *Re A*.[146] This case involved a request from the mother of a man with Down's syndrome for him to have a vasectomy. The duty to act in accordance with professional standards and the duty to act in the best interest of the patient have not 'been conflated into one requirement'.[147] Thus, the Court of Appeal held, 'it is the judge, not the doctor, who makes the decision that...(treating/not treating)...is in the best interests of the patient'.[148] Hoffman LJ, in *Bland*, felt that doctors should not 'determine the legal and moral questions...Nor do I think that the profession would be grateful to the court for leaving full responsibility for such decisions in its hands...(W)hether in those circumstances it would be lawful to provide or withhold the treatment or care is a matter for the law'.[149] This analysis reflects public opinion that doctors are accountable and patients have protectable rights. Doctors have dual obligations: to act in accordance with a responsible body of medical opinion when identifying treatment options and to act in the best interests of the incompetent patient.[150] Patients have a right to expect the legislature and/or the judiciary to protect their interests. Treatment should be withheld unless there is 'no practicable, less intrusive means of treating the condition'.[151] The *Blood* case, in which semen was surgically collected from a dying man at his wife's request, represented a gross invasion of privacy despite the doctors' good intentions.[152] Doctors often believe that decision-making is solely their preserve.[153] Consequently, the judiciary have found it necessary to set boundaries so doctors know when to refer an issue to the courts.[154] Hoffman LJ's conclusion must be correct: 'I would expect medical ethics to be formed by the law rather than the reverse'.[155] However, often the judiciary have allowed medical ethics to shape the law.[156] Consequently, doctors 'acting in accordance with their peers' feel unchallengeable.[157] Similarly,

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[142]The substituted judgment approach has critics amongst the American medical profession. See, Letters: Substituted Judgment and the Decision to Withhold Life Support. *Annals Intern.Med.* 1991;**115,**9:743-745. Note also that American courts, and some English commentators use the spelling 'judgement' - quotations will use the spelling employed by the judge or author.

[143]*Re T (Adult: Refusal of Treatment)* [1993] Fam 95 at p112 per Lord Donaldson MR. See also, *Re MB (Medical Treatment)* [1997] 2 FLR 426, at 437, *Sidaway v Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital* [1985] AC 871 at p904 and *Gillick v West Norfolk and Wisbech AHA* [1986] AC 112 at p169 and p186.

[144]*A National Health Service Trust v D* [2000] 2 FLR 677.

[145]*Airedale NHS Trust v Bland* [1993] AC 789 at p898.

[146]*Re A (Male Sterilisation)* [2000] 1 FLR 549.

[147]Ibid, at pp555 per Butler-Sloss P.

[148]Ibid, at pp555 per Butler-Sloss P. See also, *Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389.

[149]*Airedale NHS Trust v Bland* [1993] AC 789 at p834.

[150]*Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389.

[151]*Re GF (Medical Treatment)* [1992] 1 FLR 293 at p294 per Sir Stephen Brown P. See also, *Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389 at p401 per Dame Elizabeth Butler-Sloss P and p405 per Thorpe LJ.

[152]*R v Human Fertilisation and Embryology Authority ex parte Blood* [1997] WLR 806. For a discussion see: Delaney L. Fathers - Who Needs Them? - HFEA v Blood. *Family Law* 1997;**27**:261-4.

[153]See earlier chapters of this thesis andthe BMA guidance *Withholding and Withdrawing Life-prolonging Medical Treatment.* 1999 BMA, London which will be discussed in the next chapter.

[154] *Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389 at p405 per Thorpe LJ. See also: *Re B (A Minor)(Wardship: Sterilisation)* [1988] AC 199: a decision to carry the sterilisation of a minor should be made by a High Court judge not by the doctor in charge of the patient.

[155]*Airedale NHS Trust v Bland* [1993] AC 789 at p834.

[156]*See: Airedale NHS Trust v Bland* [1993] AC 789 and *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.

[157]See, *In Re B (A Minor) (Wardship: Medical Treatment)* 1981 1 WLR 1421 at p1423 per Templeman LJ. Similarly, Dr David Moor's actions were approved by many doctors yet the Crown Prosecution Service felt there was an arguable case against him regarding attempted murder: *Rv Moor* (unreported) *The Times* 12 May 2000 and Wilkinson P. Cheers as GP is cleared of murdering patient. *The Times* 12 May 1999. It is questionable, following the Harold Shipman case, whether the jury would acquit if a similar case came to the courts now.

complimenting the doctors for any errors they made in *St George's* encourages medical paternalism.[158]

In *Re S*[159], the court held sterilisation was not in her best interests as the risk of pregancy was speculative. In *Re X* the risk was more real, and if she became pregnant her family would face additional pressures, so the court granted the declaration sought.[160] Therefore, doctors consider it acceptable to consider the burden on others rather than the patient's best interests.[161] As in *Re F*[162], there is often a failure to address the issue of protecting the incompetent person, not just from pregnancy, but also from abuse.

Although the incompetent patient has a right not to be subjected to non-consensual touching, which is waived only if inhumane not to, children and incompetent adults have been allowed to donate bone marrow, and occasionally organs, to siblings with minimal, or no, interference by the courts.[163] This suggests that the physical integrity of 'incompetents' is of little value to the judiciary.[164] No English court has authorised non-therapeutic treatment to proceed in the absence of consent from a competent adult.[165] The message sent to doctors is that only those who can speak up for themselves receive protection. In *Bland*, Lord Browne-Wilkinson suggests that the court cannot use the best interests test with adults - all they can do is state that invasive treatment is lawful.[166] If correct, cases like *Re Y*[167] are incorrectly decided unless there is an unacknowledged difference between decisions made for the medical benefit of others and those made for the 'benefit' of the patient him/herself.

6.1.3.1 Refusal by Incompetent Adult Patients

The competent patient's refusal is usually held to be absolute but, where an unborn child's life is at risk, the woman's competence is questioned by the medical profession whose opinion is normally accepted by the courts.[168] The issue of undue influence, as well as pain, shock and sedation, affecting her competence was raised in *Re T.*[169] Economically, medically and ethically, treatment was indicated. However, the doctors had withheld information regarding the consequences of refusal.[170] It cannot be acceptable to withhold relevant information and then challenge on grounds of incompetence.

In *Rochdale*,[171] because the patient was resigned to death, she was not 'able...to make any valid decision about

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[158]The doctors were complimented for 'any errors' they made in *St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728, at p748. The guidelines encourage doctors to question the validity of advance directives: *St George's Healthcare NHS Trust, ex parte S* (No 2) [1998] 2 FLR 758.

[159]*Re S (Medical Treatment: Adult Sterilisation)* [1998] 1 FLR 944.

[160]*Re X (Adult Sterilisation)* [1998] 2 FLR 1124.

[161]See the discussion in earlier chapters which demonstrates this point.

[162]*Re F (mental patient: sterilisation)* [1990] 2 AC 1.

[163]There seems to be a presumption in favour of the existence of an emotional bond which is not always necessarily the case. Child B's sister was the donor for the failed bone marrow transplant (*R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055). See also: *In Re Y (Mental Patient: Bone Marrow Donation)* [1997] 2 WLR 556. American courts have also upheld such donations: *Strunk v Strunk* (1969) 35 A.L.R. (3d) 683; *Hart v Brown* (Super 1972) 29 Conn Supp 368, and (unreported) a case where a family deliberately had another child in the hope it would be a good match for the child with leukaemia: Month S. Preventing children from donating may not be in their best interests. *BMJ* 1996;**312:**241-242.

[164]See, for instance, *In Re Y (Mental Patient: Bone Marrow Donation)* [1997] 2 WLR 556. Two other potential donors existed: Feenan D. A good harvest? *Re Y (Mental Incapacity: Bone Marrow Transplant). Child and Fam.Law Q.* 1997; **9,**3:305-312 at p309.

[165]See, for instance, the American case, *McFall v Shrimp* 10 Pa D & C 3d (Allegheny County Ct 1978).

[166]*Airedale NHS Trust v Bland* [1993] AC 789 at p884F.

[167]*In Re Y (Mental Patient: Bone Marrow Donation)* [1997] 2 WLR 556.

[168]However, in *Re MB*, although the obstetrician found the patient competent, the judge disagreed: *Re MB (Medical Treatment)* [1997] 2 FLR 426 at p435.

[169]*Re T (Adult: Refusal of Treatment)* [1993] Fam 95.

[170]The case only went to court once she had lapsed into a coma. See: Brazier & Bridge, op cit n53 at p108.

[171]*Rochdale Healthcare (NHS) Trust v C* (Unreported) 3 July 1996. Referred to in *Re MB (Medical Treatment)* [1997] 2 FLR 426 at p434.

anything of even the most trivial kind'.[172] Competence was equated with rationality with the arbiters being the judiciary and/or the doctors.[173] Butler-Sloss LJ rightly objected to this unbridled professional paternalism.[174] She concluded that irrationality should mean 'a decision which is so outrageous in its defiance of logic or of accepted moral standards that no sensible person who had applied his mind to the question could have arrived at it' and 'panic, indecisiveness and irrationality in themselves do not as such amount to incompetence'.[175] It is for the doctors to decide whether 'temporary factors' are 'operating to such a degree that the ability to decide is absent'.[176] This gives the medical profession tremendous power.[177] Competence is 'a value judgment that varies from moment to moment and situation to situation'.[178] The lacuna in *St Georges* means patients in pain could be deemed incompetent.[179] This 'handing-over' of their adjudication powers by the judiciary betrays the patients they are supposed to protect from unwarranted intrusion. Also, since '(t)here may be occasions when the situation facing the authority is so urgent and the consequences so desperate that it is impracticable to attempt to comply with these guidelines...(so)...formulaic compliance with these guidelines would be inappropriate' it seems that the court's role is becoming one of protecting the doctor from civil liability in non-urgent situations.[180] The revised guidelines in *St George's* give weaker support for patient autonomy than the judgment itself which asked, 'how can a forced invasion of a competent adult's body against her will...be ordered without irremediably damaging the principle of self-determination?'[181] This suggests that the economic burden to society of a disabled woman or infant is not irrelevant.

Following the ruling in *St George's* the same judge[182] who heard the *Rochdale* case,[183] later heard *Re M* involving a fifteen year old girl refusing a heart transplant.[184] The finding that she was incompetent because she was 'overwhelmed' by the suddenness of events has ramifications for future cases.[185] It is open to the courts to decide that any patient faced with unforeseen need for major surgery will be incompetent to refuse such treatment. Despite the Court of Appeal's instructions that doctors should not apply to the courts for support in enforcing treatment if the patient is competent,[186] all the doctors will need to do now is raise the suggestion that the patient has been 'overwhelmed' by the rapid turn of events.[187] In *Re A (Conjoined Twins)* the parents

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[172] *Re MB (Medical Treatment)* [1997] 2 FLR 426 at p435.

[173] For an example of the difficulties this poses see *Hunter v British Coal Corporation* [1998] 3 WLR 685, where feelings of guilt following the death of a colleague was 'an irrational response' yet guilt is one of the seven stages of grief which everyone needs to pass through following a bereavement. Kubler-Ross E. *On Death and Dying* 1974 NBC, New York.

[174] *Re MB (Medical Treatment)* [1997] 2 FLR 426 at p435. It should be remembered that different cultures have differing attitudes towards surgical delivery of babies particularly if a woman is prized for her ability to bear children. The Caesarian section is major abdominal surgery; future deliveries usually need to be by the same route and there is the possibility that the ability of the woman to conceive and carry to term will be affected.

[175] *Re MB (Medical Treatment)* [1997] 2 FLR 426 at p437.

[176] Ibid, at p437.

[177] The exercise of the power would, no doubt, be judged using the *Bolam* test: *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582 as modified by *Bolitho v City & Hackney Health Authority* [1998] AC 232. See also: *Joyce v Wandsworth HA* [1996] 7 Med.LR 1.

[178] Wear AN, Brahams D. At the coalface: To treat or not to treat: the legal, ethical and therapeutic implications of treatment refusal. *J.Med.Ethics* 1991;**17:**131-135 at p133.

[179] *R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728. See: Jewell L. Treatment without Consent. *Family Law* 1998;**28:**774-6. However, some patients in such situations will be genuinely incompetent: *Norfolk and Norwich Healthcare NHS Trust v W* [1996] 2 FLR 613.

[180] *R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 758, Guideline (11).

[181] Where there is less urgency, the court's approval will still need to be sought: *Re F (mental patient: sterilisation)* [1990] 2 AC 1; *Airedale NHS Trust v Bland* [1993] AC 789.

[182] Sir Robert Johnson J. See: Gibb F. Judge has a history of overriding patients. *The Times* 16 July 1999.

[183] *Rochdale Healthcare (NHS) Trust v C* (unreported) 3 July 1996.

[184] *Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097.

[185] Ibid, at p1100 per Johnson J. See also: Scott R. Girl saved by heart she didn't want. *Daily Mail* 16 July 1999; Dyer C, Boseley S. A matter of life and death. *The Guardian* 16 July 1999; Dyer C, Boseley S. New heart for dying girl who refused consent. *The Guardian* 16 July 1999; Anon. Judge forces girl aged 15 to have heart transplant. *The Times* 16 July 1999.

[186] *R v St George's Healthcare NHS Trust, ex parte S (No 2)* [1998] 2 FLR 758, para ii.

[187] It is worth noting that, as will be discussed in later in this thesis, the BMA is prepared to utilise the courts in the case of pregnant women who refuse Caesarian sections although for other patients it wishes to exclude the courts from playing any role. See: BMA, *Withholding and Withdrawing Life-prolonging Medical Treatment.* June 1999 BMA, London at p24. para. 13.7.

were held 'overwhelmed' by the decision' and lacked 'consistency'.[188] Patients will only be able to protect themselves from unwanted Caesarian sections if they can demonstrate that they have considered all the consequences of a difficult labour well in advance.

In *Re S*, a Caesarian section case,[189] Sir Stephen Brown P disregarded any consideration of competence and based his decision on the American case of *Re AC* as he believed that this supported the concept that the life of the foetus should be prioritised over the principle of respect for patient autonomy.[190] *Re AC* is distinguishable from the English Caesarian section cases to date because her death from cancer was unavoidable. Subsequent decisions have been premised upon finding that the patient is temporarily incompetent as in *Re MB*, where counsel argued that, even if she were competent, the court could 'and should take into account the interests of the unborn child and balance them against the mother's interests'.[191] Such patients are described as 'mothers' although they have yet to give birth but the 'baby' is a 'foetus'. The language chosen has significance for the final decision.[192] *Re MB* held that, despite *Re S*[193], the court did not have 'the jurisdiction to take the interests of the fetus into account'.[194] *Paton* was relied upon for authority: 'The fetus[195] cannot, in English law...have a right of its own at least until it is born and has a separate existence from its mother. That permeates the whole of the civil law of this country...and...America, Canada, Australia'.[196]

Sometimes doctors wait until the patient loses capacity, before requesting court approval for treatment.[197] In *Re AC,* her refusal was overridden after unconsciousness following sedation.[198] The conflict of maternal and foetal interests meant that 'what was good for one would have been harmful to the other'.[199] Other American cases hold that the mother and (viable) unborn child are 'one'[200], suggesting that the state's interest in preserving life and the child's right to life trump the mother's right to 'privacy'. This 'oneness' was expressly rejected in *St George's*[201] although Lord Donaldson MR had previously suggested that the principle of autonomy could be qualified in the case where the choice could lead to 'the death of a viable foetus'.[202] Rhoden considers that the judicial willingness to force pregnant women to undergo surgery is tantamount to holding that a duty to rescue their unborn child exists.[203] Rhoden believes the courts are wrong to extrapolate legal

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[188]*Re A (Conjoined Twins: Medical Treatment)* op cit n77, at p52G per Ward LJ (adopting the language used by Sir Robert Johnson J who had heard the initial application).
[189]*Re S (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 671.
[190]*In re AC* 533 A2d 611 (DC App.1987).
[191]*Re MB (Medical Treatment)* [1997] 2 FLR 426 at p439.
[192]For instance, carrying out a termination of pregnancy can result in a 'recognisable baby', a 'foetus' or 'end products of conception' being 'delivered', 'passed', 'evacuated' or 'extracted'.
[193]*Re S (Adult: Refusal of Medical Treatment)* [1992] 4 All ER 671.
[194]*Re MB (Medical Treatment)* [1997] 2 FLR 426, at p440, per Butler-Sloss LJ.
[195]Note the Americanised spelling.
[196]*Paton v British Pregnancy Advisory Service Trustees* [1979] QB 276, per Sir George Baker P at p279. *R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728 confirms the lack of protection afforded unborn children.
[197]The cases of *Tameside and Glossop Acute Services Trust v CH* [1996] 1 FLR 762 and *Norfolk and Norwich Healthcare (NHS) Trust v W* [1996] 2 FLR 613 should be distinguished since the findings of incompetence were not unreasonable.
[198]*In re AC* 533 A2d 611 (DC App.1987).
[199]Kennedy I, Grubb A. *Medical Law: Text and Materials* 2nd Edn 1994 Butterworths, London at p355.
[200]*Raleigh Fitkin-Paul Morgan Memorial Hospital v Anderson* (1964) 201 A 2d 537 (NJ Sup.Ct.) and *Jefferson v Griffin Spalding County Hospital Authority* (1981) 274 SE 2d 457 (Sup.Ct.Georgia).
[201]*R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728 at pp742-6. Authority came from *Attorney-General's Reference (No3 of 1994)* [1997] 3 WLR 421 at p428 per Lord Mustill and at p440 per Lord Hope of Craighead and *Re F (In Utero)(Wardship)* [1988] Fam 122 at p143 per Balcombe LJ.
[202]*Re T (Adult: Refusal of Medical Treatment)* [1993] Fam 95 at p102.
[203]Rhoden N. The Judge in the Delivery Room: The Emergency of Court-Ordered Caesareans (1986) 74 *Cal.LR* 1951. Reprinted in Kennedy I, Grubb A. *Medical Law: Text and Materials* 2nd Edn 1994 Butterworths, London at pp359-366.

duties from moral obligations. Alternatively, a general duty to assist third parties could be developed[204] Typically the judge hears 'only the doctor's side and will learn little or nothing of the risks of surgical delivery'.[205] If the patient feels threatened she may abscond, placing herself and the unborn child at risk.[206] Trying to enforce unwanted treatment may result in no care being received.

The revised *St Georges* guidance shows the power of doctors to influence the judiciary at the expense of patient autonomy because it emphasises that, in 'urgent' situations, it need not be complied with.[207] Since doctors decide 'urgency' these guidelines give little protection for the patient. More cases like *Re S,* where the court held that the danger to the woman and unborn child justified the haste of its decision, are liable to occur.[208] Patients may have uncertain or fluctuating capacity but any ability to exercise autonomy should be encouraged and enhanced.[209] Acting paternalistically may be easier but proxy decision-makers regularly fail to make the same decision the patient would have made themselves.[210] Difficult behaviour may be interpreted as evidence of incompetence as in *Re D.*[211] A distorted view of his 'best interests', ignoring the fact that his psychiatric problems were controllable, enabled a decision to be made that dialysis was not in his best interests. The decision could have been based on protecting staff from violence.[212]

6.1.3.2 Refusal by Minor Patients

Minors over the age of 16 years have the status to consent to medical treatment[213]. *Gillick* established that those under this age may have capacity to consent if of 'sufficient understanding and intelligence to enable him/her to understand fully what is proposed'[214] since, 'parental right yields to the child's right to make his own decision'.[215] A 'full understanding and appreciation of the consequences both of the treatment in terms of intended and possible side-effects and equally important, the anticipated consequences of a failure to treat' is required.[216] If a child has fluctuating understanding s/he is held *Gillick* incompetent.[217] It is for the doctors

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[204]See: Draper H. Women, forced Caesarians and antenatal responsibilities. *J.Med.Ethics* 1996;**22:**327-333. Draper proposes that women should be held responsible if the baby suffers harm through their refusal of assistance.

[205]Rhoden N, in Kennedy I, Grubb A. *Medical Law: Text and Materials* 2nd Edn 1994 Butterworths, London at p365. Rhoden points out that a court-ordered Caesarian leaves the patient and his/her family without redress if the scenario they fear actually occurs unless there is negligence on the part of the doctors in performing the operation. In one case the author of this thesis knows of, a woman afraid of death under anaesthesia was pressurised into a Caesarian section in 1998. She never recovered consciousness and her death was attributed to pituitary failure resulting from the stressful situation. In *R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728 the solicitor actually lied to the judge and was rebuked by the Court of Appeal (at p756).

[206]As in *Re F (In Utero)(Wardship)* [1988] Fam 122.

[207]*St George's Healthcare NHS Trust v S (No 2)* [1998] 2 FLR 758.

[208]*Re S (Adult: Refusal of Medical Treatment)* [1993] 1 FLR 26.

[209]For instance, diminished competence in an old person may be no more than evidence of a treatable urinary tract infection. See also: Law Commission Report No 231 *Mental Incapacity* 1995 HMSO, London para 3.14 and Lord Chancellor's Department *Making Decisions* (Cm 4465) October 1999 The Stationery Office, London.

[210]Hardwig J. The Problem of Proxies with Interests of Their Own. *J.Clinical Ethics* 1993; **4:**20-27. See also, Stolman CJ et al. Evaluation of patient, physician, nurse and family attitudes towards Do-Not-Resuscitate orders. *Arch.Intern.Medicice* 1990;**150**:653-658.

[211]*Re D (Medical Treatment: Mentally Disordered Patient)* [1998] 2 FLR 22. As Cretney points out, the declaratory process was used to protect the healthcare providers from being held culpable for the patient's subsequent deterioration and eventual death: Cretney S. Comment: Re D (Medical Treatment: Mentally Disordered Patient) *Family Law* 1998;**28:** 324-5.

[212]Hospital staff should not have to be subjected to violent attacks: Zollo MB, Derse A. The Abusive Patient: Where do you draw the line? *American Journal of Nursing* 1997;**97,**2:31-36. See also, the 'Zero Tolerance' government stance on this issue taken in: Department of Health. *We don't have to take this: Resource Pack.* L20/002 November 1999 Department of Health, Wetherby. However, it should be noted that this was silent regarding the issue of violence from mentally ill patients, many of whom are in control of their actions as was the patient in *Re D.* The author of this thesis wrote to Alan Milburn, Secretary of State for Health, concerning this point and received written assurances that staff caring for the mentally ill are not expected to tolerate violence and that further guidance will be issued from the Department of Health in Autumn 2000. At the time of writing (February 2001) no further guidance has yet been issued.

[213]Family Law Reform Act 1969 s8.

[214]*Gillick v West Norfolk and Wisbech AHA* [1985] WLR 830 at p858D per Lord Scarman.

[215]Ibid, at p855H, per Lord Scarman.

[216]*Re R (A Minor)(Wardship: Consent to Treatment)* [1992] Fam 11 at p26 per Lord Donaldson MR.

[217]*Re R (A Minor)(Wardship: Consent to Treatment)* [1992] Fam 11.

to decide whether the child has the requisite level of understanding and intelligence. This may be affected by the doctor's personal bias; the nature of the proposed treatment; prior knowledge of the child and his/her circumstances and possibly other factors, so similar children may be rated differently. The majority, in *Gillick*[218], felt that to apply the law rigidly, insisting on a fixed age barrier between incompetence and competence, fails to recognise the natural development of competence with maturity.[219] The more sheltered an upbringing, the less likely a child is to be found competent.[220] In *Re L*, the patient, possibly due to her epilepsy, was badly scalded in a bath.[221] She refused life-saving blood transfusions because of her Jehovah's Witness faith. Regarding *Re E*[222], a fifteen year old boy with leukaemia, Brazier and Bridge question whether the patient's refusal of blood transfusions was 'free choice'[223] although Bailey-Harris suggests that 'teenagers with deeply held convictions' should be regarded as mature and 'entitled to their full autonomy rights'.[224] The Court of Appeal, in *Re W,*[225] accepted that the anorexic patient was *Gillick* competent,[226] but held that refusing treatment differed from consenting since s8 of the Family Law Reform Act 1969 only refers to 'consent'.[227] The more serious the consequences of refusal, the less likely the court will hold the patient competent.[228] Lord Donaldson MR, in *Re R*,[229] seemed to consider *Gillick* competence to differ from the ordinary competence of an adult. He held that the test for competence should be modified '(i)n the case of fluctuating mental disability to take account of that misfortune'.[230] This suggests that maturing competency differs from declining competency otherwise anyone who is subject to fluctuating capacity should be held incompetent. Elderly patients of fluctuating capacity could have treatment decisions made on their 'good days' overturned on their 'bad days'. This would bring the medical profession and/or the courts into disrepute. Douglas argues that in *Re R* supra, the Court of Appeal rejected the right of a competent person to make mistakes and 'entrenched not welfare, but paternalism, as its guiding principle in wardship'.[231] In contrast, Bridgeman believes that the *Gillick* judgment shows the House of Lords held that the welfare of the child was paramount.[232] In most cases involving children it is economically, medically and ethically correct to try to save life.

The Children Act 1989 gives the court powers to order medical or psychiatric examination and treatment.[233] It also embodies a right for the competent child to refuse medical examination yet the courts have not extended this to the logical conclusion of treatment refusal.[234] If a *Gillick* competent child refuses medical examination, the doctor will be unable to make a diagnosis and recommend treatment. A competent child is unlikely to refuse examination because s/he will recognise the need for diagnosis. Consequently, a refusal of examination could be evidence of incompetence. Once the examination has revealed the problem, the courts then hold that

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[218]*Gillick v West Norfolk and Wisbech AHA* [1986] AC 112.
[219]See the expert opinion in *Re S (A Minor)(Medical Treatment)* [1994] 2 FLR 1065 at p1072 and Brazier & Bridge, op cit n53 at p106.
[220]*Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810. In contrast, see *Re B (Wardship: Abortion)* [1991] 2 FLR 426.
[221]*Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810.
[222]*Re E (A Minor)(Wardship: Medical Treatment)* [1993] 1 FLR 386. See also, *Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810.
[223]Brazier & Bridge, op cit n53 *passim*.
[224]Bailey-Harris R. 'Patient Autonomy - A Turn in the Tide?' In Freeman M, Lewis A (Eds) *Law and Medicine: Current Legal Issues* Vol 3. 2000 Oxford University Press, Oxford pp127-140 at p137.
[225]*Re W (a minor) (medical treatment)* [1993] Fam 64, albeit with reservations expressed by Lord Donaldson MR at pp80-81.
[226]*Gillick v West Norfolk and Wisbech AHA* [1986] AC 112.
[227]*Re W (a minor) (medical treatment)* [1993] Fam 64.
[228]See, for instance, *Re E (A Minor) (Wardship: Medical Treatment)* [1993] 1 FLR 386 where the leukaemic patient was nearly 16 years old.
[229]*Re R (A Minor)(Wardship: Consent to Treatment)* [1992] Fam 11.
[230]Ibid, at p26.
[231]Douglas G. The retreat from *Gillick. MLR* 1992;**55:**569-576 at p573.
[232]Bridgeman J. Old enough to know best? *Legal Studies* 1993:69-80 at p71.
[233]These powers exist if the court has made orders under s38 (interim care or supervision); s43 (child assessment); s44 (child protection).
[234]If the child is of sufficient understanding to make an informed decision, the child is given the right to refuse medical/psychiatric examination (Children Act 1989 s38(6), s43(8), s44(7) and paras 4(4)(a) and 5(5)(a) of Schedule 3).

the child lacks the capacity to refuse treatment.[235] The child's welfare is the paramount consideration although the court should take into account the factors in s1(3) Children Act 1989. The child's wishes are only one factor to be considered although the court should 'not lightly override (the child's) decision on such a personal matter as medical treatment, all the more so if that treatment is invasive'.[236] How the child's views are sought has a relevance not recognised by the courts.[237] Bridgeman criticises the harsh treatment of *W* who had already been dealt with harshly by fate.[238] Sentiment for the individual should not cloud the decision-making process - fate has dealt harshly with many of those for whom the courts have to resolve issues of medical treatment.

The child's refusal is not determinative.[239] It can be overridden by anyone with parental responsibility giving consent[240] although Lord Donaldson MR suggested that once a child has the requisite maturity and understanding, his/her parents lose the right of determination.[241] Eekelaar argues that if parental rights regarding decisions concerning the child are lost once the child has capacity to consent for themselves then it cannot be possible for the crown to retain the right to 'intervene in the lives of children'.[242] However, Douglas holds that the *parens patriae* power of the state is not lost since, as *Re R* suggests, 'the court's powers are wider than those of parents' and it is acting not only custodially but protectively.[243] If the child has mental illness, statutory powers exist for enforced treatment although there is marked reluctance to use them.[244] Reluctance to use the Mental Health Act left a child barricaded in her room, manipulating her family and not receiving the help she needed.[245] Theoretically, where the child is *Gillick* competent, the court might uphold the child's refusal.[246] Douglas argues that although treatment is allegedly in the child's 'best interests', in practice, alternative medical views can legitimately be held so refusals of treatment should be approached more cautiously than consent with regard to overturning the patient's decision since a greater interference with autonomy is involved.[247] This is particularly true in the case of *Re M* where the court was told 'no other medical option was available'[248] although life-saving alternatives which may have been medically better as well as more acceptable to her did, at the time, exist.[249]. It is worth noting that in *Re M*, parental consent had been given for the heart transplant, yet the doctors were still unwilling to proceed without the authority of the court.[250] This suggests great anxiety regarding decisions involving physical maim (albeit therapeutic) and the

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[235] *Re L (Medical Treatment Gillick Competence)* [1998] 2 FLR 810. See also, Comment by Rebecca Bailey-Harris: *Family Law* 1998;**28:**591-2.

[236] *Re W (a minor) (medical treatment)* [1993] Fam 64 at p88 per Balcombe LJ.

[237] Terry L, Campbell A. Hearing Children's Voices. Paper presented at the 3rd Annual Trevor Clay Memorial Conference, Philosophy in Nursing at Middlesex University 15 September 2000. See also: Terry L, Campbell A. Hearing Children's Voices: Are We Listening? *British Journal of Nursing* (forthcoming - accepted for publication 27 February 2001).

[238] Bridgeman J. Old enough to know best? *Legal Studies* 1993:69-80 at p79. See also, Huxtable R. *Re M (Medical Treatment: Consent)* Time to remove the 'flak jacket'? *CFLQ* 2000;**12,**1:83-88.

[239] *Re W (a minor) (medical treatment)* [1993] Fam 64 at p81 per Lord Donaldson.

[240] *Re R (A Minor)(Wardship: Consent to Treatment)* [1992] Fam 11.

[241] Ibid, at p24.

[242] Eekelaar J. The Emergence of Children's Rights Oxford J.Leg.Studies 1986:161 at p181

[243] Douglas G. The retreat from *Gillick.MLR* 1992;**55:**569-576 at p573. See: *Re R (A Minor) (Wardship:Consent to Treatment)* [1992] Fam 11 at p25.

[244] In *Re R (A Minor)(Wardship: Consent to Treatment)* [1992] Fam 11 the alternative solution would have been to section her under the Mental Health Act 1983 if she became disturbed and transfer her to a psychiatric hospital.

[245] *South Glamorgan CC v W and B* [1993] 1 FLR 574.

[246] *Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097 could have been such a case.

[247] Douglas G. The retreat from *Gillick.MLR* 1992;**55:**569-576 at p576.

[248] *Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097 at 1099.

[249] Ibid. One alternative, a piggyback transplant using a donor heart would have carried a slightly reduced long-term survival rate but the patient would have kept her own heart. The other alternative, used successfully with a patient suffering from the same viral endocarditis condition, was to piggyback a small mechanical heart. In one case where this was done as a temporary measure a year before *Re M*, when a donor heart became available six months later, the surgeons found the patient's own heart had fully recovered and there was no need to carry out a transplant. Rogers L. Mini heart pump to end transplants. *The Times* 9 April 2000. Heart transplants in young females carry particular problems with regard to contraception and pregnancy.

[250] *Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097 at p1099. The doctors were possibly concerned that the child might attempt to resist surgery. There would be a definite risk, in such a situation, that a heart attack could be triggered, and they could be held culpable. Recent BMA guidance suggests to doctors how and when restraint or force can be used on children: British Medical Association. *Consent, Rights and Choices in Health Care for Children and Young People*. December 2000 BMA, London at pp113-115.

long-term acquiescence of the patient.[251]

Brazier and Bridge persuasively argue that when the patient is a teenager, the finding of competence rests more upon the outcome of the decision than its rationality since '(r)ationality appears to be acquired on a person's 18th birthday'.[252] Had M been nearly 18 years old, her wishes might have been respected, given that heart transplants are more likely to be considered abhorrent than other transplants or blood transfusions. Brazier and Bridge suggest that '(a)s long as minority necessarily imposes a degree of dependency on the minor, and until...the hormonal disturbances of adolescents are safely in the past, society might well adopt a more sceptical approach to autonomy'.[253] Fortunately, 'irrational' decisions are no longer evidence of sectionable insanity[254] or many women with 'mood swings' would be at risk.[255] 'Our society...has as its first principle, the respect for the individual, and that society and government exist to protect the individual from being invaded and hurt by another'.[256]

The welfare of the child is 'the first and paramount consideration'.[257] Although Lord Woolf MR accepts the principle of 'non-interference by the courts in areas of clinical judgment' where avoidable,[258] it is not enough to 'hope' the patient will 'return to full health' as in *Re L*[259] or that the child's life will be normal.[260] Judges, and doctors, must recognise that some patients prefer death to 'life in the wings' if they are to adequately respect patient self-determination.[261] This means it is important to identify treatment alternatives. The seeking of independent medical advice in *Re A (Conjoined Twins)* is new and to be encouraged.[262] The problem judges have is in critiquing medical information.[263] Gostin correctly challenges the way some judgments are based solely upon the efficacy of the proposed treatment.[264] Differences of opinion will 'reflect the individualistic values to which medicine has always subscribed, particularly in the case of clinicians who have reached the top of the hierarchy and feel they possess sufficient expertise to act on the basis of their own judgement'.[265]

Sometimes, distress for others seems decisive. *Re L* favoured treatment because non-treatment would be 'distressing...for all those who were attending her'.[266] The child in *Re M* recognised that her family would be

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[251]Ibid, at p1100. Reservations were expressed by Vivienne Nathanson, head of ethics at the British Medical Association (Was the judge right? Against. *The Guardian* 16 July 1999)and John Evans, chairman of the British Organ Donor Society. *The Sun* 16 July 1999. See also: O'Hear A. From a child of 15, the meaning of life: commentary. *Daily Mail* 16 July 1999.

[252]Brazier & Bridge, op cit n53 at p107.

[253]Ibid, at p109.

[254]*R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728.

[255]It is accepted that the 'mood swings' in *Re R (A Minor)(Wardship: Medical Treatment)* [1992] Fam 11were manifestations of psychotic mental illness.

[256]*McFall v Shrimp* 10 Pa D & C 3d (Allegheny County Ct 1978) per Flaherty J. Approved in *R v St George's Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728 at 743 per Butler-Sloss LJ.

[257]*Re R (A Minor)(Wardship: Consent to Medical Treatment)* [1992] Fam 11 at p32 per Farquharson LJ.

[258]*Rv Portsmouth NHS Trust ex parte Glass* [1999] 2 FLR 905 at p908.

[259]*Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810.

[260]Re *A (Conjoined Twins: Medical Treatment)* op cit n77 at p21A and p21F per Ward LJ reporting the opinions of two of the medical experts.

[261]*Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810, at p813 per Sir Stephen Brown P.

[262]*Re A (Conjoined Twins)* [2001] 1 FLR 1.

[263]For instance, the twins were born with an imperforate anus which means excreta cannot be voided. Normally, an opening is surgically- made within a day of birth. It is not clear whether this had been performed for these twins. If performed, the surgery could have had an adverse effect upon Mary and perhaps the court could have considered whether it may have been better not to have done this. Similarly, the pictorial evidence suggests that Mary has hydrocephalus, and Dandy Walker syndrome is a form of hydrocephalus, but the evidence given the court was that she had not yet developed hydrocephaly. Similarly, Mary's heart was described as normal in structure but enlarged and 'not squeezing well'(*Re A (Conjoined Twins)* op cit n77, at p13F per Ward LJ. The judges do not seem to have understood the mechanics of what happens if two non-synchronised pumps are placed on the same circuit.

[264]Gostin. A Moment in Human Development: Legal Protection, Ethical Standards and Social Policy on the Selective Non-Treatment of Handicapped Neonates *Am J. Law & Medicine* 1985;**11**:32-41.

[265]Ham C, Pickard S. *Tragic Choices in Health Care: The case of Child B.* 1998 King's Fund, London at p22.

[266]*Re L (Medical Treatment Gillick Competence)* [1998] 2 FLR 810 at p811 per Sir Stephen Brown P.

sad if she died.[267] However, Butler-Sloss P doubts 'whether third party interests should ever be considered'.[268] An appropriate approach to the evidence of distress caused to third parties was taken in *Re ZM* where Bennett J held that expert opinion is not conclusive, it should be 'weighed and judged by the court'.[269]

6.1.4 Family Prefers Non-treatment

Families may seem more interested in the patient's wealth than his/her best interests.[270] Any advice that non-treatment is preferable has to be cautiously interpreted. Decisions have to be made in the best interests of incompetent patients so neither the doctors' not the parents'/family's views are decisive. To date, there have been no English cases challenging the tendency of doctors to decide the older patient's treatment with family members even though the patient is competent.[271] However, this is a possibility under the Human Rights Act 1998. In contrast, protection of the incompetent patient's interests requires that the normal exclusivity of the decision-making process is displaced. Since the determination of 'best interests' is primarily for doctors, it can be difficult for families or carers to secure recognition of their view of the patient's interests. This is particularly true where the patient is being treated for 'mental illness'. In *Bournewood*, the patient, incapable of exercising self-determination, was lawfully treated although not 'voluntary' - a decision which deprives those like him of protection from unfettered medical paternalism.[272] *Bournewood* reflects a retrograde step from the pro-patients' rights stance taken in *ex parte W* and *ex parte L.*[273] Lords Steyn and Nolan were particularly concerned at the absence of adequate protection for so vulnerable a patient.[274]

Non-treatment may be requested by families in order to prevent the patient burdening them. Some decisions are influenced by the patient's secondary characteristics such as dementia or mental retardation even where treatment is likely to cure/control the primary problem.[275] When doctors believe treatment is appropriate they are likely to refer the decision to the courts as in *Re B*, where the child had Down's syndrome and needed life-saving emergency surgery, but the parents refused consent.[276] In *Re B*, the Court of Appeal concluded 'it is not for this court to say that life of that description ought to be extinguished'.[277] Barring treatment on grounds of age; incompetence or inability to cope alone does exactly this.

'Best interests' generally requires predicting the quality of life with and without treatment. Schaffner et al suggest treatment must be rational, redeeming (benefits outweigh risks), respectful of patient's wishes and take account of 'quality of life and cost.'[278] It is impossible to determine how often situations involving conflicts over whether to treat or not arise. The lack of peer/judicial review contributes to the 'haphazard and often

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[267] *Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097.
[268] *Re A (Male Sterilisation)* [2000] 1 FLR 549 at p556.
[269] *Re ZM and OS (Sterilisation: Patient's Best Interests)* [2000] 1 FLR 523 at p533. The medical expert suggested the patient suffered distress because she knew she was distressing her family (at p533).
[270] *Re S (Hospital Patient: Court's Jurisdiction)* [1995] 1 FLR 1075.
[271] There are numerous complaints made to Hospital Complaints Managers concerning this tendency: Personal Communication.
[272] *R v Bournewood Community and Mental Health Trust, ex parte L* [1999] 1 AC 458.
[273] *R v Hallstrom and another, ex parte W (No 2), R v Gardner and another, ex parte L.* [1986] 2 All ER 306. See also, for a strong critique of the Bournewood decision: Diesfeld K. Neither consenting nor protesting: an ethical analysis of a man with autism. *J. Med. Ethics* 2000;**26**:277-281.
[274] *R v Bournewood Community and Mental Health Trust, ex parte L* [1999] 1 AC 458 at p492 per Lord Nolan and at p497 per Lord Steyn.
[275] For instance, see *Re Y (Mental Incapacity: Bone Marrow Transplant)* [1997] 2 WLR 556 and *Re D (Medical Treatment: Mentally Disordered Patient)* [1998] 2 FLR 22.
[276] *In re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421.
[277] *(A Minor) (Wardship: Medical Treatment)*[1981] 1 WLR 1421.
[278] Schaffner KF, et al. Philosophical, ethical and legal aspects of resuscitation medicine. *Critical Care Medicine* 1988;**16**:1069-1076 at p1070.

arbitrary nature of the practice'.[279] Caring for the disabled presents 'substantial burdens to parents, family, and even taxpayers' which not all are prepared to take on.[280] The burdens on others are irrelevant under the Children Act 1989,[281] despite the recent BMA advice that 'the implications for the family of treatment or non-treatment' should be considered when establishing a child's best interests.[282] Medical advances are likely to result in more cases where 'the rights of adults need to be balanced against the consequences on children'[283] *Re J* held 'the correct approach is for the court to judge the quality of life the child would have to endure if given the treatment'.[284] Dunn LJ said the court could not 'hide behind the decision of the parents or the decision of the doctors'.[284A] Later, lack of resources was considered relevant.[285] Twelve years on, the court in *Bland* hid[286] but in *Re A (Conjoined Twins)* the difficulities were confronted by the Court of Appeal more openly.[287] Whilst it was medically appropriate to attempt separation, it is unclear that it was either legally or ethically appropriate. The economic appropriateness was not addressed but that seems dubious. At times, patients' lives have been reduced to lists, with minimal acknowledgement of ethical values, to establish 'best interests'.[288] *Re A (Conjoined Twins)* shows how difficult it is to determine 'best interests'. Ward LJ held the separation was not in Mary's best interests, although it was allowable,[289] but Walker LJ was 'scarily clear (that) a short, terribly disabled and possibly painful life was a life not worth living'[290] consequently, separation was in Mary's best interests.[291] Sanctity of life, quality of life, the parents' views and the lawfulness of the operation were all considered. Since Mary was 'designated for death' anyhow, the separation was allowed in order to save the life of Jodie.[292] Kennedy and Grubb criticise the interpretation of the 'best interests' test as a 'quality of life' test since then it is merely normative not factual.[293] Doctors develop their decision-making models using the case law as guidance. Consequently, whilst quality of life is '*established* as a matter of principle' by the courts, 'it will ordinarily be *applied* in particular cases' by doctors thus allowing value judgments to influence the decision.[294] Had Jodie shown signs of brain damage it is unlikely that the court would have overruled the parents' objection. Quality of life arguments are rejected by American courts since failing to treat because of disability could constitute child abuse.[295] In *Re A (Conjoined Twins)*, Ward LJ suggested that refusing to give one twin the chance of life could constitute abuse.[296]

Despite the caution given by Lord Bingham MR: '(i)t is important...that there should not be a belief that what the doctor says is the patient's best interest *is* the patient's best interest'[297] doctors' opinions are clearly

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[279]Robertson JA. Legal aspects of Withholding Treatment From Handicapped Newborns: Substantive Issues. *J.Health Politics, Policy and Law* 1986; **11**,2:215-230 at p215.
[280]Ibid, at p217.
[281]*Re A (Conjoined Twins)* op cit n77, at p52G per Ward LJ.
[282]British Medical Association, op cit n250 at p4.
[283]*Re R (Contact: Human Fertilisation and Embryology Act* 1990) [2001] 1 FLR 247 at p251H per Hedley HHJ.
[284]*Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33 at p55 per Taylor LJ.
[284A]*Re B (A Minor) (Wardship: Medical Treatment)* [1981] 1 WLR 1421 per Dunn LJ at p1424G.
[285]*Re J (A Minor)(Wardship: Medical Treatment)* [1992] Fam 165 at p176 per Balcombe LJ.
[286]*Airedale NHS Trust v Bland* [1993] AC 789.
[287]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.
[288]*Re A (Male Sterilisation)* [2000] 1 FLR 549 at p560 per Thorpe LJ.
[289]*Re A (Conjoined Twins)* op cit n287, at p46G. Brooke LJ, at p62F, concurred with Ward LJ on this point.
[290]Foster C. Rocks and Hard Places. *Solicitors Journal* 13 October 2000 pp922-923 at p923.
[291]*Re A (Conjoined Twins)* op cit n287, at p118E.
[292]Ibid, at p54A per Ward LJ.
[293]Kennedy I, Grubb A. *Medical Law: Text and Materials* 2nd Edn 1994 Butterworths, London pp1240-1247, in particular, at p1240.
[294]Ibid, at p1240. For an example of this in practice, see *Rv Portsmouth NHS Trust ex parte Glass* [1999] 2 FLR 905 and *Royal Wolverhampton Hospitals NHS Trust v B* [2000] 1 FLR 953.
[295]Child Abuse, Prevention and Treatment Act as amended in 1984.
[296]*Re A (Conjoined Twins)* op cit n287 at p57B-D per Ward LJ (discussion regarding parental cruelty towards Jodie (contrary to s1 Children and Young Persons Act 1933)).
[297]*Frenchay Healthcare NHS Trust v S* [1994] 1 FLR 485 at p493.

preferenced over parents'.[298] This has extended to conducting screening tests against parental wishes as in *Re C*.[299] In that case, the mother left England rather than submit the baby to testing which, if it revealed the child to be HIV[300] positive, would have led to doctors requesting permission to give treatment against her wishes. Medical paternalism and the early involvement of social services created barriers to good care that could possibly have been overcome. Only rarely is the refusal of treatment for minors allowed - if the doctors wish to treat, they usually can. The only recent exception has been regarding a child in need of a liver transplant whose parents removed him from the U.K..[301] It was not clear that treatment was ethically appropriate and it was unlikely that the child would survive into adulthood even if the transplant went ahead. Economically it lacked appropriateness. Family privacy was upheld.[302] The emphasis placed on the parents' opinion in *Re T*[303] because they were healthcare professionals can not be seen as decisive following *Re MM.*[304] Indeed, in *Re T*, the court was possibly 'taken in by their professional knowledge'[305] which highlights the problems inherent in expecting courts of law to make decisions in complex areas of medicine and ethics. However, the court's decision in *Re MM* seems particularly flawed given the lack of a proper diagnosis for the child's condition, the temporary nature of residency in this country and the lack of accessibility of immunoglobulins in Russia. Whatever treatment was given was 'experimental' in nature and the parents seemed more knowledgeable than the English doctors.[306] To 'hope' that arrangements could be made whereby the child could receive continued treatment after his return home seems to fail to take into account his long-term best interests.[307] Following *Re A (Conjoined Twins)* lack of parental support for the long-term treatment of the child also no longer seems relevant.[308] Presumably, if the parents cannot, or will not, care for the child, the state will assume responsibility but, where this is uncertain, perhaps heroic life-saving attempts should not be attempted.[309]

6.2 Doctor is Anti-treatment

6.2.1 Patient is competent

6.2.1.1 Patient accepts non-treatment

Consensual withholding or withdrawing of treatment agreed with the full understanding and agreement of the patient presents no problem providing the doctor's advice is not negligent. Where the patient is very elderly, very immature or of a compliant or suggestible personality, the voluntariness of the consent may be suspect. 'Well-behaved' patients may defer to doctors. The healthcare environment can disempower.[310] Doctors may

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[298]See, for example, *Re T (Wardship: Medical Treatment)* [1997] 1 FLR 502. For examples of parents wanting treatment but doctors believing it best not to treat see: *Re C (Medical Treatment)* [1998] 1 FLR 384. See also *Royal Wolverhampton Hospitals NHS Trust v B* [2000] 1 FLR 953.

[299]*Re C (HIV Test)* [1999] 2 FLR 1004.

[300]Human Immunodeficiency Virus which is believed to be the cause of AIDS (Aquired Immunodeficiency Syndrome).

[301]*Re T (Wardship: Medical Treatment)* [1997] 1 FLR 502. *Re J (Specific Issue Orders: Child's Religious Upbringing and Circumcision)* [2000] 1 FLR 571 can be distinguished on the grounds that the circumcision was not medically indicated.

[302]Cedar S, Terry L. Genes and Genealogy. *Family Law* 2000;**30**:744-747 at p746.

[303]*Re T (a minor) (medical treatment)* [1997] 1 WLR 242.

[304]*Re MM (Medical Treatment)* [2000] 1 FLR 224.

[305]Freeman M. 'Can we leave the best interests of very sick children to their parents?' In Freeman M, Lewis A (Eds) *Law and Medicine: Current Legal Issues* Vol 3. 2000 Oxford University Press, Oxford pp257-268 at p258.

[306]Ibid, at p231.

[307]Ibid, at p233.

[308]*Re A (Conjoined Twins)* [2001] 1 FLR 1.

[309]Ibid, at p26D-G per Ward LJ.

[310]Tassano F. *The Power of Life or Death: A Critique of Medical Tyranny.* 1995. Duckworth, London at pp39-40.

forget that withholding relevant information affects 'free choice'.[311] *Sidaway* held that the *Bolam* [312] principle should apply to the nature of the information given to the patient by the doctor.[313] The doctor should 'provide his patient with the information needed to enable the patient to consider and balance the medical advantages and risks alongside other relevant matters, such as, for example, his family, business or social responsibilities of which the doctor may be only partially, if at all, informed'.[314] However, even when the patient questions the doctor about proposed treatment s/he is not entitled to be given full information: 'the amount of information...must depend on the circumstances'.[315] The courts have often privileged beneficence over autonomy.[316] Decisions to move from a curative to a palliative model of care should be informed, not imposed, and subject to the 'reasonable doctor' test.[317] If a 'reasonable person in the patient's situation' would have regarded certain information as significant the doctor could be liable.[318] The doctor's duty could extend to disclosure that appropriate treatment is being withheld because of a shortage of resources or a bar on treatment. Otherwise, the patient's consent to the course of treatment proposed, or 'consent' to the withholding of the undisclosed alternative, is uninformed and the patient is unable to access treatment privately or lobby purse-holders. *St George's* suggested that if the patient's competence is to be questioned, doctors can no longer exercise 'therapeutic privilege' to withhold relevant information.[319] The analysis carried out earlier in this thesis shows that decisions are manipulated by doctors and the nature and amount of information is controlled. However, the *St George's* guidelines issued later show a retreat: whilst the court should be told of 'any alternative treatment'[320] the patient is only entitled to information regarding 'the proposed treatment'.[321] Therefore, Harrington's scepticism as to whether the 'liberal critics of current medical law' espousal of respect for autonomy and informed consent can overturn the inherent paternalism of the medical profession is well-founded.[322] Particularly regarding adolescents, there is little judicial support for fully informing the patient.[323] If the judiciary are ambivalent regarding protecting autonomy, it is unsurprising that doctors are also.

Decisions can be defended as consensual although they may not truly represent patient wishes. For instance, someone may, altruistically, prefer to offer treatment opportunities to others. There is a hint of this in *Re A (Conjoined Twins)* with the suggestion that Mary would, if possible, offer the chance of life to Jodie.[324] There is no legal difficulty over competent, informed adult patients and their doctors agreeing that treatment should be withdrawn or withheld. English law takes a laissez-faire approach reflecting a societal view that healthcare is a private matter between patient and doctor. For instance, compulsory vaccinations are not required. Dare's proposal in favour of compulsory vaccination would mean accepting that the state has a right to override the objections of individuals, even when there is no threat to public safety, so radically altering the relationship between law and medicine.[325] The trend is for doctors to practice 'partnership' in decision-making with patients

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[311]See: *Re L (Medical Treatment: Gillick Competency)* [1998] 2 FLR 810 and Commentary: McCafferty C. Won't Consent? Can't Consent! Refusal of Medical Treatment. *Family Law* 1998;**29:**335-6.

[312]*Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.

[313]*Sidaway v Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital* [1985] AC 871.

[314]Ibid, at p886B per Lord Scarman. See also, p904G per Lord Templeman.

[315]*Blyth v Bloomsbury HA* [1993] 4 Med LR 151 at p160 per Neill LJ.

[316]See discussion in *Sidaway,* op cit n313, at pp886-7 per Lord Scarman.

[317]The non-therapeutic nature of palliative care should not reduce the level of information required: *Gold v Haringey HA* [1987] 2 All ER 888.

[318]*Sidaway,* op cit n313, at p889H per Lord Scarman.

[319]*St George's Healthcare NHS Trust v S (No 2)* [1998] 2 FLR 758 para ii.

[320]*St George's Healthcare NHS Trust v S (No 2)* [1998] 2 FLR 758.

[321]See: Bailey-Harris R. Comment. *Family Law* 1998;**28:**663-4.

[322]Harrington JA. Privileging the medical norm: liberalism, self-determination and refusal of treatment. *Legal Studies* 1996;**16:**348-367.

[323]See: *Re L (Medical Treatment: Gillick Competence)* [1998] 2 FLR 810.

[324]*Re A (Conjoined Twins)* op cit n308, at p112B per Walker LJ.

[325]Dare T. Mass immunisation programmes: some philosophical issues. *Bioethics* 1998; **12,**2:125-149.

rather than paternalism.[326] English law generally avoids enforcing unwanted treatment even if clinically appropriate or forcing doctors to provide treatment.[327] An issue not yet considered by English courts is whether a child under eighteen can consent to treatment withdrawal if this is what the doctors recommend even though his or her parents want treatment to continue. The court could uphold the child's autonomy by interpreting the decision as consent to the treatment plan (moving from curative to palliative care) or simply uphold the medical profession's 'rights'.

6.2.1.2 Patient wants treatment

If a doctor is not prepared to offer or continue treatment, this is usually because s/he believes this would be inappropriate on clinical or ethical grounds. If the reason is a shortage of resources, the patient may chose to challenge using judicial review.[328] In other situations, the easiest option may be for the patient to find another doctor who is prepared to give treatment.[329] In the case of Child B, it was held that further treatment would not be in her best interests, and possibly not in accordance with a responsible body of medical opinion, yet there was no legal opposition to her receiving treatment which was provided privately.[330] Ham and Pickard have examined this case and the protagonists' motivations in detail.[331] They conclude that the father's refusal to accept non-treatment was a 'direct challenge' to the doctors involved in her care.[332] The difficulty facing patients is identifying a suitable alternative doctor since access to specialists is governed via GPs who may be reluctant to incur the additional costs of referral for second opinion. Tertiary referrals also cost money which could be spent elsewhere. Patients are increasingly likely, like Child B's father, to actively seek medical information particularly via the internet.[333] The difficulty lies in understanding and interpreting it but patients, and families, are no longer silent partners in medicine.

6.2.2 Patient lacks competence to decide

Imminent, unavoidable death constitutes well-established grounds for ending treatment.[334] *Bland* decided that the correct question was not whether it was in Tony's best interests to die but whether it was in his best interests not to continue treatment. *Re M and Re H* holds that *Bland* is correct both at common law and under the European Convention on Human Rights although, since the Human Rights Act 1998 came into force, judges are not bound by the decision in *Bland*.[335] Neither Bland, nor the patient in *Re AC*,[336] died with dignity yet, every time a non-treatment decision resulting in the patient's death is made, the real conclusion is that

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[326]Lord Walton of Detchant. Dilemmas of life and death: Part One. *J.Roy.Soc.Med.*1995;**88**:311-5 at p314.

[327]*Rv Portsmouth NHS Trust ex parte Glass* [1999] 2 FLR 905 at p908.

[328]See discussion earlier.

[329]This was what one mother alleges she had to do when doctors allegedly refused to book her in for antenatal care and delivery because they felt it better to carry out a late termination rather than deliver expensive care to a non-viable neonate: Personal communication. The mother eventually went to the newspapers who reported some of her allegations: Horsnell M. Parents say hospital chose to let baby die. *The Times* 27 November 2000.

[330]*R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055. In *Consent, Rights and Choices in Health Care for Children and Young People*, the BMA implies, by the way it has placed the Child B case study in the section entitled 'The medical duty to act only within one's sphere of competence' that the doctors who treated her initially were correct not to be persuaded into giving her other treatment with which they were unfamiliar, but it also possibly implies that the doctor who did give further treatment was exceeding his competence: British Medical Association op cit n250 at pp209-211.

[331]Ham C, Pickard S. *Tragic Choices in Health Care: The case of Child B.* 1998 King's Fund, London.

[332]Ibid, at p 35.

[333]Ibid, at pp2-3.

[334]*Re C (A Baby)* [1996] 2 FLR 43 (concerning a baby left brain-damaged following meningitis). See also, *A National Health Service Trust v D* [2000] 2 FLR 677 (involving non-resuscitation of a severely brain-damaged child).

[335]*NHS Trust A v Mrs M and NHS Trust B v Mrs H* [2000] EWHC 29 (25 October 2000) paras 18, 28 and 31 per Dame Elizabeth Butler-Sloss P. Judgment available on www.bailii.org accessed 28 November 2000. Also reported in *The Times* 29 November 2000.

[336]*In re AC* 533 A2d 611 (DC App.1987).

death is best.[337] Honesty is preferrable. Lords Goff, Lowry and Brown-Wilkinson adopted the 'balance of benefits and burdens' model but Lord Goff also used 'futility'.[338] It is difficult to comprehend how artificial feeding, which is achieving its aim of providing fluids and nutrition, is 'futile'.[339] Lord Mustill controversially held that permanently insensate patients have 'no interests'[340] - a similar approach to the Supreme Court of New Jersey in *Peter* which held that since such patients 'could not experience any pain, suffering, joy, satisfaction, or well-being any benefits-burdens analysis was equally inapplicable.'[341] Therefore, it was unnecessary to prove that the burdens of continued existence outweighed the benefits of life.

Dworkin argues that '(a)lmost everyone shares, explicitly or intuitively, the idea that human life has objective, intrinsic value'[342] but it is 'irrational' to prolong some lives.[343] The difficulty is in drawing the line, inside which patients live, outside which they die. In *Re C,* the court concluded (despite evidence that her condition was stable) that she was 'dying', therefore it was appropriate to withhold treatment enabling her to 'die peacefully with the greatest dignity and the least of pain, suffering and distress'.[344] Although a court may order the transfer of the patient to another doctor[345] judges increasingly defer to clinical opinion even though the patient's condition differs from the criteria given by a 'body of medical professionals' for withdrawing treatment[346] or in the face of opposition by relatives.[347] In *Re H* the patient's 'best interests' required that artificial feeding was discontinued although she was not in a vegetative state.[348] Cretney suggests that, although it is hard to hold that the decision was in her best interests, it was made in the best interests of all concerned.[349] In another case, Bodley J concluded that the breakdown in trust between the parties required that the doctors were given permission to not-treat the child if they thought fit, not just because this was in the patient's best interests but as 'a kindness to the parents'.[350] The case law leads doctors to believe that their opinion can, and generally should, take precedence and that their decisions to withhold or withdraw treatment are virtually impregnable.

The determination of 'best interests' relies on estimations of quality of life in cases where doctors are advocating non-treatment. Gostin believes '"quality of life" is employed as a signal by those who believe that

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[337] *Airedale NHS Trust v Bland* [1993] AC 789, and, similarly, the severely handicapped child in *Re C (A Minor) (Wardship: Medical Treatment)*[1989] 2 All ER 782.

[338] *Airedale NHS Trust v Bland* [1993] AC 789 at p868 per Lord Goff since 'there was no prospect of any improvement in his condition'.

[339] For a useful examination of how 'futility' is misused see: Zucker MB & Zucker HD. *Medical futility and the evaluation of life-sustaining interventions.* 1997 Cambridge University Press, Cambridge.

[340] *Airedale NHS Trust v Bland* [1993] AC 789 at p897E. See also, the American case *In the Matter of Hilda M Peter* 529 A 2d 419 (1987). See also: Robertson JA. Legal aspects of Withholding Treatment From Handicapped Newborns: Substantive Issues. *J.Health Politics, Policy and Law* 1986; **11,**2:215-230 at p226. Robertson's approach seems mirrored by Lord Mustill.

[341] *In the Matter of Hilda M Peter* 529 A 2d 419 (1987) at p424.

[342] Dworkin R. *Life's Dominion* 1993 Harper Collins, London at p67.

[343] Dworkin R. *Sovereign Virtue: The theory and practice of equality.* 2000 Harvard University Press, London at p313.

[344] *Re C (A Minor) (Wardship: Medical Treatment)*[1989] 2 All ER 782. *In re B (A Minor) (Wardship: Medical Treatment)* 1981 1 WLR 1421 was distinguished due to the different quality of life (B had Down's syndrome).

[345] This issue was considered in *Re T (Wardship: Medical Treatment)* [1997] 1 FLR 502. American courts will also transfer cases: Paris JJ et al. Physicians' refusal of requested treatment. *NEJM* 1990;**322,**14:1011-1013 at p1012. The Court of Appeal did not discuss whether to order the transfer of the conjoined twins in *Re A (Conjoined Twins)* op cit n308, to Great Ormond Street though it seems clear that their interests would be better served by the experienced team operating. Great Ormond Street later wrote to the Department of Health asking for the transfer: Rogers L. Doctors may not operate on twins. *The Sunday Times* 1 October 2000.

[346] See *Re D (adult: medical treatment)* [1998] 1 FCR 498 (the patient's condition did not meet three of the criteria for diagnosis of persistent vegetative state according to the guidelines of the Royal College of Physicians). See also: *Frenchay Healthcare NHS Trust v S* [1994] 1 FLR 485 at p492 where there was evidence that the patient had 'volitional behaviour'.

[347] See: *Re G* [1995] 2 FLR 528, *Royal Wolverhampton Hospitals NHS Trust v B* [2000] 1 FLR 953, *Re C (Medical Treatment)* [1998] 1 FLR 384 and *Rv Portsmouth NHS Trust, ex parte Glass* [1999] 2 FLR 905.

[348] *Re H (A Patient)* [1998] 2 FLR 36. For information regarding inaccurate diagnosis of PVS and the ability to track objects as the earliest sign of recovery see Andrews K. Recovery of patients after four months or more in the persistent vegetative state. *BMJ* 1993; **306:**1597-1601. For a commentary on the lack of dignity associated with withdrawal of nutrition see: McLean S. End of life decisions and the law. *J. Med. Ethics* 1996;**22:**261-2, in particular, at p262.

[349] Cretney S. Comment on *Re H. Family Law* 1998;**28:**460.

[350] *Royal Wolverhampton Hospitals NHS Trust v B* [2000] 1 FLR 953 at p957.

selective non-treatment decisions are too delicate and complex to be governed by any coherent legal or ethical standard. Accordingly, its advocates seek to maintain the decision-making process within a confidential doctor/patient framework'.[351] Quality of life is subjectively assessed with 'those in the lower social classes clearly showing a higher tolerance over what is an acceptable degree of handicap'.[352] This could indirectly affect what the law considers acceptable since 'parents (in social classes I and II) are not only likely to be more articulate but are also likely to share the class values of those responsible for formulating legislation and for implementing it'.[353] Keyserlinck asserts: 'For society, medicine and law...quality of life can and does mean many very different things...some of the uses to which the concept is put are definitely opposed to and in conflict with the sanctity of life principle'.[354] Per Lord Woolf MR in *Glass*: 'The principles of law are clearly established but how you apply those principles to particular facts is often very hard to anticipate'.[355] The doctors in *Glass* treated the severely disabled boy with pneumonia with diamorphine, a respiratory depressant. The family were outraged and, *en masse*, invaded the ward and resuscitated him.[356] With 'these sensitive and difficult'[357] decisions Lord Woolf suggests the best course is for the parent to agree to 'the course which the doctors are proposing to take'.[358] Counsel for the Trust in Bland admitted that 'one should not leave the definition of what is and what is not a 'worthwhile' life to be decided by a doctor'.[359] In deferring to medical opinion, the judiciary fail to protect the weak.

Re J held: 'it is settled law that the court's prime and paramount consideration must be the best interests of the child'.[360] There was a 'strong presumption' in favour of preserving life except in 'exceptional circumstances' with Taylor LJ stating 'it can not be too strongly emphasised that the court never sanctions steps to terminate life'.[361] Although, like *Bland*, respect for sanctity of life would mean *J* was resuscitated, the court instead evaluated his 'best interests' by considering the quality of his life. The doctors stressed the 'unpleasant and distressing nature of the treatment' and the probable worsening of J's condition so it was held that 'to add such distress and the risk of further deterioration to an already appalling catalogue of disabilities was clearly capable...of producing a quality of life which justified the stance of the doctors'. [362] Similarly, in *Re C,*[363] the court held: 'whilst the sanctity of life is vitally important, it is not the paramount consideration. The paramount consideration here is the best interests of little C'.[364] The failure of the court to give any place to the parents' religious views has been criticised as 'paternalistic and...culturally imperialistic'.[365] Whilst each life is of equal value, individual quality of life is 'matters relevant' to be placed in the decision-making scales.[366] A major factor could be whether the patient is in pain as suggested by Templeman LJ in *Re B*: 'this court..(has)..to decide whether the life of this child is demonstrably going to be so awful that in effect the child

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[351]Gostin, op cit n164 at p39.
[352]Shepperdson B. Abortion and euthanasia of Down's syndrome children - the parents' view. *J.Med.Ethics* 1983;**9:**152-7 at p156.
[353]Ibid, at p157.
[354]Keyserlinck E. *Sanctity of Life or Quality of Life: Report for the Law Commission of Canada.* Canadian Law Reform Commission.1979 at p50.
[355]*Rv Portsmouth NHS Trust ex parte Glass* [1999] 2 FLR 905 at p910 per Lord Woolf MR.
[356]Three of them were later jailed for this: *R v (1) Davies (2) Wild (3) Hodgson* (2000) CA 28 July 2000 Unreported.
[357]*Rv Portsmouth NHS Trust ex parte Glass* [1999] 2 FLR 905 at p911 per Lord Woolf MR.
[358]Ibid, at p910 per Lord Woolf MR.
[359]*Airedale NHS Trust v Bland* [1993] AC 789 at p849.
[360]*Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33 at p53.
[361]Ibid.
[362]Ibid, at p56.
[363]*Re C (Medical Treatment)* [1998] 1 FLR 384.
[364]*Re C (Medical Treatment)* [1998] 1 FLR 384 at p393. See also, *Royal Wolverhampton Hospitals NHS Trust v B* [2000] 1 FLR 953 at pp955-956 per Bodley J. For a discussion of parental opinion in such cases see: Loughrey J. Medical Treatment - the Status of Parental Opinion. *Family Law* 1998;**28:**146-9.
[365]Mason JK, McCall Smith RA and Laurie GT. *Law and Medical Ethics* 5th Edn. 1999 Butterworths, London at p251.
[366]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 at p48C per Ward LJ.

must be condemned to die'.[367] However, in *Bland*, Butler-Sloss LJ felt that 'concentration exclusively upon pain is...an unacceptable approach'.[368] The verdict in *Cox* confirms that pain is no defence for ending life unlawfully.[369]

Doctors have adopted the 'demonstrably so awful model'[370] but lack the impartiality of the judiciary.[371] Doctors use 'awful' descriptors to influence the court.[372] Judges adopt them.[373] In *Re A (Conjoined Twins)* the descriptors used regarding Jodie and Mary's separate conditions and future quality of life were based on emotion not just science.[374] The parents were held unduly pessimistic regarding Jodie.[375] The obtaining of independent medical advice was novel and highly commendable but the judges seemed not to know how to interpret all the information appropriately. Brooke LJ discussed the literature regarding reconstructive surgery which indicates that multiple surgeries will be necessary and the outcome unsatisfactory yet did not challenge the doctors who said they were 'hopeful' minimal surgery would be necessary and the outcomes good.[376] American courts hold that, 'at the moment of live birth there does exist a human being entitled to the fullest protection of the law' and reject quality of life considerations.[377] Brooke LJ held that the rights to life of Mary and Jodie had 'equal status' so, in cases of this sort, 'it is wholly illegitimate to introduce considerations that relate to the quality, or potential quality, of each sister's life'.[378] Ward LJ, in contrast, held that, it is legitimate 'to bear in mind the actual quality of life each child enjoys and may be able to enjoy'.[379] Hence, 'Mary may have a right to life, but she has little right to be alive'.[380] Brooke LJ's approach suggests why the 'first come, first served' allocation is accepted medical practice so the current user of a resource is not evicted when another potential user of that resource, with a better prognosis, appears. If Ward LJ is correct,a quality of life assessment should determine whether the resource is taken away from the present user.[381] Perhaps current medical practice regarding ITU beds and cots is better explained in terms of the doctor's duty of care than sanctity of life. Hence, the ITU doctor only owes a duty of care to the current user because the potential user has not yet been admitted under his/her care and is currently under the care of another doctor. It is unsatisfactory that access to life-saving treatment depends upon 'ownership' of patients.

Few patients have the 'exceptional circumstances' of *J* although they may suffer some disability. Were these the sort of patients that Donaldson MR 'left the door open' for when he explained '(w)hat is at issue...is not a right to impose death but a right to choose a course of action which will fail to avert death.'?[382] In general,

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[367]*In re B (A Minor) (Wardship: Medical Treatment)* 1981 1 WLR 1421, 1424. See also, Doyal and Wilsher's argument in Doyal L, Wilsher D. Towards guidelines for withholding and withdrawal of life-prolonging treatment in neonatal medicine. *Arch.Dis.Child.* 1994; **70:** F66-F70, at F66-67.

[368]*Airedale NHS Trust v Bland* [1993] AC 789 at p820.

[369]*R v Cox* [1992] 12 BMLR 38. Johnson J had been particularly concerned by the image of twin Mary being in pain and unable to cry out: *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 at p28F-G per Ward LJ.

[370]*In re B (A Minor) (Wardship: Medical Treatment)* 1981 1 WLR 1421 at p1424. See also the evidence of the neonatologist in *Re A (Conjoined Twins)* op cit n369, at pp22H-23A per Ward LJ.

[371]See the discussion earlier in this thesis.

[372]Cramb A. Doctor left my premature baby to die. *The Daily Telegraph* 10 June 1997. The parents of Rebecca Cassidy sought an inquiry into why the doctor refused to treat the baby.

[373]See, for instance, *Airedale NHS Trust v Bland* [1993] AC 789 at p813 per Bingham MR.

[374]*Re A (Conjoined Twins)* op cit n369, pp10E-14C per Ward LJ.

[375]Ibid, at p104D per Walker LJ.

[376]Ibid, at pp66-67 per Brooke LJ. The surgeon's views are given in the judgment of Ward LJ at pp20E-21A.

[377]Merrick JC. Critically Ill Newborns and the Law. *J. Legal Med.* 1995; **16:**189-209 at p200. See also, Clark KL. Intensive Care Treatment Decisions: the Roots of Our Confusion. *Pediatrics* 1994;**94,**1:98-101.

[378]*Re A (Conjoined Twins)* op cit n369, at p71F per Brooke LJ.

[379]Ibid, at p53H.

[380]Ibid, at p54D per Ward LJ.

[381]This issue was considered in *Airedale NHS Trust v Bland* [1993] AC 789 at p 896 by Lord Mustill.

[382]*Re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam 33 at p55 and approved by Butler-Sloss LJ in *Airedale NHS Trust v Bland* [1993] AC 789 at p820.

the American approach appears based on a presumption of 'personhood'[383] which is refuted by ethicists like Doyal and Wilsher who argue that 'even healthy infants do not possess these attributes (of personhood)'.[384] Separovic, however, believes that this is 'dangerous and dehumanising'.[385] Certainly, a change in approach by English courts is evident since 1989.[386] In *Re J*, 'the court's high respect for sanctity of human life imposes a strong presumption in favour of taking all steps capable of preserving it save in exceptional circumstances'.[387] Two years on, the court could 'conceive of no situation where it would be a proper exercise of its jurisdiction...to order a doctor...to treat a child in a manner contrary to his clinical judgement'[388] and even if consent were given, it would be subject to the availability of resources and the willingness of the doctors to treat.[389] In 1993, it was held that sanctity of life 'fundamental though it is, is not absolute'.[390] Keown suggests that the courts consistently confuse 'sanctity of life' with 'vitalism' so adopt a 'Quality of life' approach instead.[391] Close analysis of *Re A (Conjoined Twins)* suggests that, despite reference to Keown's article[392], and Ward LJ's emphasis that each life had equal worth, a vitalist approach was taken towards Jodie in contrast to a 'Quality of life' approach with Mary when resolving the court's duty towards each child.[393] This opened the way to hold that the doctrine of necessity allowed doctors to kill Mary.

In the U.S.A. substituted judgment tends to be used for adults who have had competence. This focuses on the known or probable views of the patient so is based more on a patient-preference model than a medical outcomes model. Keyserlinck suggests comparing the qualities the patient currently has with the qualities 'deemed by *this* patient (or if incompetent or irreversibly comatose, by the patient's agents) to be normative and desirable.'[394] In *Peter* a proxy already existed as well as evidence of the patient's prior wishes thus enabling the patient's views to be respected.[395] In *Quinlan*, it was eventually held that her father could be appointed her legal guardian and take medical decision on her behalf.[396] *In re Jobes* authorised the substituted judgment approach to be taken by the patient's family utilising their knowledge of the patient's personality and prior reactions to healthcare matters in the absence of any known patient preferences about life-sustaining treatment.[397] The declaration in *Re R* gave his parents a novel power of veto.[398] However, in *Glass*, no such power was given to his mother nor any reason given for this judicial inconsistency.[399] It can be speculated that in *Re R*, the parents were working with the doctors whereas in *Glass* the relationship had clearly broken down with the hospital.

Recently, English courts have strayed into the language of substituted judgment. In *Re J* the decision was

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[383] *People v Chavez*, 77 Cal. App. 2d 621, 176 P. 2d 92 (1947). For a discussion of this issue see: Robertson JA. Legal aspects of Withholding Treatment From Handicapped Newborns: Substantive Issues. *J.Health Politics, Policy and Law* 1986; **11,**2:215-230, in particular, at p218.

[384] Doyal L, Wilsher D. Towards guidelines for withholding and withdrawal of life prolonging treatment in neonatal medicine. *Arch.Dis.Child.* 1994; **70:** F66-F70 at F67.

[385] Separovic ZP. Massa carnis or human beings? (On Abortion, Euthanasia and Care of Defective Baby). *Jus Mecicum* 1984 Centrum Voor Medish Recht, Rijkuniveriteit, Gent at pp 169-172 at p169.

[386] *Re F (mental patient: sterilisation)* [1990] 2 AC 1.

[387] *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33 at p55 per Taylor LJ.

[388] *Re J (A Minor) (Child in Care: Medical Treatment)* [1993] Fam 15 at p30 per Leggatt LJ.

[389] *Re J (A Minor) (Wardship: Medical Treatment)* [1991] Fam 33 at p28 per Donaldson MR.

[390] *Airedale NHS Trust v Bland* [1993] AC 789 at p864 per Lord Goff.

[391] Keown J. Restoring moral and intellectual shape to the law after Bland. (1997) 113 LQR 481. See, in particular, p501.

[392] *Re A (Conjoined Twins)* op cit n369 at pp41G-43C per Ward LJ.

[393] Ibid, at pp53E-54F, Section IV Family Law para 10, in particular p54D per Ward LJ.

[394] Keyserlinck, op cit n354 at p51. His emphasis.

[395] *In the Matter of Hilda M Peter* 529 A 2d 419 (1987).

[396] *Re Quinlan* 70 NJ 10 (1976). See also: Devettere RJ: *Practical Decision Making in Healthcare Ethics: Cases and Concepts* 1995 Georgetown University Press, Washington DC at pp168-174; Weir, op cit n3 at pp108-110 and MacKay RD; Terminating life-sustaining treatment - recent US developments. *J.Med.Ethics* 1988;**14:**135-139 at p135.

[397] *In the Matter of Nancy Ellen Jobes*, 529 A2d 434 (1987). See also, MacKay RD; Terminating life-sustaining treatment - recent US developments. *J.Med.Ethics* 1988;**14:**135-139.

[398] *Re R (Adult: Medical Treatment)* [1996] 2 FLR 99.

[399] *R v Portsmouth Hospitals NHS Trust, ex parte Glass* [1999] 2 FLR 905.

based on whether continued life would be 'intolerable to that child'.[400] Despite rejection of this approach in *Bland*[401] and *Re Y*[402], in *Re R*[403] the court considered whether the adult patient's life, following resuscitation, would be 'so afflicted as to be intolerable'.[404] Patients like *J*, *R* and *G* have no knowledge of 'normative and desirable' conditions so basing decisions on what would be 'intolerable' to the patient, is merely 'a fiction' imposing the views of the doctor or judge.[405] Ward LJ doubts that substituted judgment is 'good law'.[406] However, when Walker LJ relates how the climber who survived against all odds told the other 'You did right' the implication is that, if Twin Mary could speak, she would tell Jodie to cut herself free likewise.[407]

6.2.3 Potential criminal liability of doctor

6.2.3.1 Causing death

Concerns exist regarding the question of causation of death in civil and criminal law if treatment is withheld or withdrawn.[408] The courts, generally, consider withholding treatment and withdrawing treatment identical.[409] However, a difference seems to be acknowledged regarding the 'ordinary' versus 'extraordinary' treatments.[410] Murder charges were considered against two doctors in California who removed 'life support systems'.[411] Conspiracy to murder charges were brought against the parents and doctors of conjoined twins in America.[412] In recent years, the position seemed to be that providing the doctor acts in accordance with recognised medical practice, a charge of murder, attempted murder or conspiracy to murder will not be brought.[413] *Re A (Conjoined Twins)* challenges this view.[414] First, the best interests of the patient have to be established and this will take into account recognised medical practice, then the lawfulness of the action must be considered.[415]

In *Conroy*, it was held that the cause of death following withdrawal of nasogastric feeding would be due to her 'underlying medical condition, which included her inability to swallow'.[416] In *Peter*, it was held that a patient dies not because of the withdrawal of dialysis but because 'his underlying disease has destroyed the proper functioning of his kidneys'.[417] Weir suggests that by 'rejecting any moral or legal difference between withholding and withdrawing life-sustaining treatment, the courts may have been communicating to physicians

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[400] *Re J (A Minor) (Wardship: Medical Treatment)* [1990] 3 All ER 930, 945 per Taylor LJ. Bodley J took a similar approach in *Royal Wolverhampton Hospitals NHS Trust v B* [2000] 1 FLR 953 at p956.
[401] *Airedale NHS Trust v Bland* [1993] AC 789 at p872B per Lord Goff.
[402] *In Re Y (Mental Patient: Bone Marrow Donation)* [1997] 2 WLR 556 at p560 per Connell J.
[403] *Re R (Adult: Medical Treatment)* [1996] 2 FLR 99. See also Comment by Rebecca Bailey-Harris: [1996] *Family Law* pp535-6.
[404] *Re R (Adult: Medical Treatment)* [1996] 2 FLR 99 at p108.
[405] Per Lord Mustill in *Airedale NHS Trust v Bland* [1993] AC 789 at p895.
[406] *Re A (Conjoined Twins)* [2001] 1 FLR 1 at p41G.
[407] Ibid, at p112B.
[408] Ibid. In particular, see the discussion of the doctrine of double effect in the judgment of Brooke LJ at p75B-G.
[409] House of Lords Select Committee on Medical Ethics Report 1993-4 HL 21-I para 251. See also, *Airedale NHS Trust v Bland* [1993] AC 789 at p879 per Lord Browne-Wilkinson and Doyal L, Wilsher D. Towards guidelines for withholding and withdrawal of life prolonging treatment in neonatal medicine. *Archives of Disease in Childhood* 1994;**70:**F66-F70 at F68.
[410] See *Airedale NHS Trust v Bland* [1993] AC 789 at pp878-9 per Lord Browne-Wilkinson. See also, Blank RH. Treatment of Critically Ill Newborns in Australasia. *J.Legal Med.* 1995; **16:**211-226 at p222 and Gillon R. *Philosophical Medical Ethics* 1986 John Wiley & Son, London at pp140-7.
[411] Towers B. Public debate on issues of life and death. *J.Med.Ethics* 1983;**9:**113-5.
[412] Moreno JD. Ethical and legal issues in the care of the impaired newborn. *Clinics in Perinatology* 1987;**14,**2:345-359,349. The case was later dropped.
[413] There seems to be another proviso - that of the doctor keeping quiet about his or her actions. Dr David Moor, was held to have brought prosecution on himself, and so was liable to pay one third of his defence costs: Wilkinson P. Cheers as GP is cleared of murdering patient. *The Times* 12 May 1999.
[414] *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.
[415] Ibid, Section IV Family Law para 4 at p35E-G per Ward LJ.
[416] *Matter of Claire Conroy* 486 A.2d 1209 (1985) at 1226.
[417] *In the Matter of Hilda M Peter,* 529 A2d 419 (1987) at p428.

that neither...is tantamount to homicide - as long as the available treatment is reasonably regarded as futile or contrary to the patient's best interests'.[418] Weir notes Fletcher's argument that the courts may be wrong and, rather than admitting consensual withholding or withdrawing life-sustaining treatment is suicide or euthanasia, they discourage legal submission on the issue.[419] Fletcher suggests that death in these circumstances is not because of illness but 'a consequence of the decision to die'.[420] Weir argues that only in cases of neglect or deliberate intention to kill should the doctor be held the legal cause of death since, when the courts hold that discontinuation of treatment is 'in the patient's best interests', this 'strongly suggests that the injury or disease process already at work will cause the patient's death' so, whilst it may be a causative factor, it is not the main cause.[421] Therefore, whilst both a physiological and a decisional cause of death may operate, only one should be considered the legal cause.[422] However, whilst the Court in *Re A (Conjoined Twins)* accepted that Mary was 'designated for death', the doctors were held to have 'murderous intent'.[423] Weir's analysis could not save the doctors from criminal liability for causing death.[424] Only if intentional killing is sometimes lawful could the doctors escape liability. Judicial selectiveness regarding the principal cause and the demand for greater 'blameworthiness' in the case of omissions which Clarkson[425], in his analysis of *Lowe*[426], has interpreted as evidence of reluctance to convict for omissions was of no avail in *Re A (Conjoined Twins)* because surgical separation is a positive act.[427]

Parents have a duty to care for their minor child;[428] doctors for their patients[429] and those who care for an elderly or disabled person[430] or take on responsibility for another[431]. Duties can also arise under statute.[432] If medical care is considered appropriate, for a person with 'custody, charge or care' to withhold it for reasons such as religious beliefs[433], neglect[434] or lack of finances[435] or lack of medical facilities in their homeland[436] may mean they are held culpable. Omissions may not attract blame in the way positive acts do.[437] *Re B*[438] held that surgery should proceed, but indicated that it is lawful for parents to make decisions which would allow their child to die.[439] In *R v Arthur*[440], Farquharson J advised the jury that if the doctor's action amounted merely to 'a course of management...that represents a holding operation' rather than a positive act 'likely to kill the

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[418]Weir, op cit n3 at p311.
[419]Ibid, at p312. Citing Fletcher J: The Courts and Euthanasia. *Law, Medicine and Healthcare* Winter 1987-8;15:224-5. Suicide is not unlawful now (s1 Suicide Act 1961) but aiding, abetting, counselling or procuring a suicide is unlawful (s2 Suicide Act 1961). See: *Attorney-General v Able* [1984] 1 All ER 277.
[420]Weir, op cit n3 at p313.
[421]Ibid, at p313.
[422]Ibid.
[423]*Re A (Conjoined Twins)* op cit n414, at p56B per Ward LJ.
[424]Ibid, at p56F per Ward LJ.
[425]Clarkson CMV, Keating HM. *Criminal Law, Text and Materials* 2nd edn. 1990 Sweet and Maxwell, London at p131.
[426]*R v Lowe* [1973] 1 QB 702.
[427]*Re A (Conjoined Twins)* op cit n414, at p56G per Ward LJ.
[428]*R v Downes* [1875] 13 Cox CC 111.
[429]*Barnett v Chelsea& Kensington Hospital Management Committee* [1968] 1 All ER 1068.
[430]*R v Instan* [1893] 1 QB 450.
[431]*R v Stone and Dobinson* [1977] 1 QB 354.
[432]S1 Children and Young Persons Act 1933 requires that persons over 16 years old caring for a minor child owe a duty not to neglect, abandon or expose that child to anything that will cause 'unnecessary suffering or death'.
[433]For instance, *R v Senior* [1899] 1 QB 283 and *Re A (Conjoined Twins)* op cit n414.
[434]*R v Instan* [1893] 1 QB 450.
[435]*R v Proctor, R v Gamble* [1918] 13 Cr App.R. 134.
[436]See: *Re MM (Medical Treatment)* [2000] 1 FLR 224 and *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.
[437]See, *R v Lowe* [1973] QB 702 and doubt cast on its approach in *R v Sheppard* [1981] AC 394.
[438]*In Re B (A Minor) (Wardship: Medical Treatment)* 1981 1 WLR 1421.
[439]However, if the child is a ward of court or the court has to arbitrate between doctors and parents, the welfare of the child becomes paramount. See: *In Re B (A Minor) (Wardship: Medical Treatment)* 1981 1 WLR 1421at p1424 per Dunn LJ and *Re A (Conjoined Twins)* op cit n436, at p32H per Ward LJ.
[440]*R v Arthur* (1981) 12 *BMLR* 1. For a discussion see: de Cruz P. 'The Leonard Arthur Case: Legal and Moral Implications' in de Cruz P, McNaughton D (Eds) *By What Right? Studies in Medicine, Ethics and the Law.* 1989 at pp-16. Penrhos Publications, Newcastle.

child' accompanied by 'intent' the doctor should not be found guilty of attempted murder. Kennedy and Grubb particularly criticise these instructions and the failure to acknowledge that 'allowing nature to take its course' may mean that the doctor is in breach of a duty to act to prevent this'.[441] Others submit that 'an omission to provide such a child with food and the ordinary necessities of life ought to be equated with an act causing death'.[442]

Robertson considers it possible that once a doctor has begun caring for a patient, the resulting legal duty cannot be terminated by third parties such as parents.[443] One reason Robinson suggests is that, in providing information regarding prognosis, the doctor imperils the child so then the doctor is under a duty to save the child.[444] This lacks plausibility since the doctor has a positive duty to inform the decision-makers. The Court of Appeal was divided over whether the doctors, or the hospital, were under a positive obligation to refer the Siamese twins case to court. Ward LJ held it would have been 'a perfectly acceptable response for the hospital to have bowed to the weight of the parental wish however fundamentally the medical team disagreed with it. Other medical teams may well have accepted the parents' decision'.[445] However, later, Ward LJ suggests, like Walker LJ,[446] that the parents in *Re A (Conjoined Twins)* failed 'to recognise their conflicting duty to save Jodie'.[447] His concentration camp analogy is offensive and inapposite since the situation in which the choice arises is created in one scenario by a moral agent choosing to act evilly and in the other by nature (or God whom Ward LJ presumably does not suggest is evil).[448] *Re A (Conjoined Twins)*[449] leaves doctors caring for conjoined twins or babies with, for example, short bowel disorder, uncertain as to when, or whether, they must refer cases to court.

Perhaps the difference between cases like *Re J* (1993)[450], *Re C* (1998)[451] and *R v Arthur* is that physiological cause will be the legal cause only when there is a 'strong suggestion' that the patient would have died anyhow[452] ie. is 'designated for death'.[453] Perhaps the truth is that judges require life to have some meaning for the patient before they will consider the doctor's actions in withdrawing or withholding life-sustaining care legally culpable. Non-legal persons are unprotected by the criminal law.[454] Anencephalic, severely brain-damaged or vegetative patients may likewise lack protection. This seems evident in the discussion in *Re A (Conjoined Twins):* 'is Mary a "reasonable creature"?'[455] or just a 'parasitic attachment'.[456]

Wilson and Smith suggest that Lord Goff interprets the law on causation as being that, providing the patient's best interests guide the doctor's actions, the doctor is not the legal cause of death - death will simply be a

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[441]Kennedy I, Grubb A. *Medical Law: Text and Materials* 2nd Edn 1994 Butterworths, London at p1249. Such 'holding' practices have raised concerns over 'backdoor euthanasia': Horsnell M. Police check hospitals over 'backdoor euthanasia'. *The Times* 6 January 1999.
[442]Smith JC, Hogan B. *Criminal Law* 7th Edn. 1992 Butterworths, London at p50.
[443]Robertson JA. Legal aspects of Withholding Treatment From Handicapped Newborns: Substantive Issues. *J.Health Politics, Policy and Law* 1986; **11**,2:215-230 at p219.
[444]Ibid.
[445]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 at p27C per Ward LJ.
[446]Ibid, at p114B-G per Walker LJ.
[447]Ibid, at p53B per Ward LJ.
[448]Ibid, at p53C per Ward LJ.
[449]Ibid, Section II para 14 at p27 'The nature of these proceedings' per Ward LJ.
[450]*Re J (A Minor) (Child in Care: Medical Treatment)* [1993] Fam 15.
[451]*Re C (Medical Treatment)* [1998] 1 FLR 384.
[452]However, even if treatment is withheld or withdrawn, humane care must not be: *Airedale NHS Trust v Bland* [1993] AC 789.
[453]*Re A (Conjoined Twins)* op cit n445, at p54A per Ward LJ.
[454]See, for example, *Attorney General's Reference (No 3 of 1994)* [1996] 2 All ER 10.
[455]*Re A (Conjoined Twins)* op cit n445, at pp69H-71F per Brooke LJ.
[456]Ibid, at p100G per Walker LJ.

natural occurrence.[457] They interpret *Malcherek* as holding the chain of causation had not been broken because the doctors were acting 'in pursuit of a duty demanded of them by society', not as voluntary agents.[458] Hastening death seems acceptable, even now to the extent of 'sacrifice'[459] but not all countries take a similar approach.[460] Does this mean that if Parliament expects doctors to consider the public purse when deciding who and how to treat, the doctor is not the cause of death when treatment is withheld or withdrawn? Presumably it does, but it must be questioned whether the government in such a case is acting in accordance with what the electorate really desires. Most believe that the doctor's role is to save lives and everyone expects 'their' doctor to only act in 'their' best interests. Possibly such duties are 'decontextualised' so no positive obligation towards any individual exists.[461] Where the 'best interests' of two or more are in direct conflict doctors who preference the life of one over another could be criminally culpable.[462] However, when restrictions are placed by healthcare commissioners, the doctor can legitimately claim to be acting as an involuntary agent of the rationing process. Were it not for the fact that the criminal law focuses on the actions of individuals, hence the difficulty over succeeding with corporate manslaughter charges, health authorities must surely be held to have caused the death of all the patients they rejected. The legitimacy of the purchaser's, or commissioner's, action could be challenged as to whether it is 'in pursuit of a duty demanded of them by society' as most have little real public input. Criticism of 'postcode rationing' fosters belief that those responsible are blameworthy. The failure of judicial review challenges does not mean that resource allocation is fair.

6.2.3.2 Doctrine of double effect`

The doctrine of double effect has been adopted as a means of avoiding holding the administration of pain relief which shortens the patient's life the legal cause of death.[463] Provided the intention is therapeutic, and in the patient's 'best interests', death is considered a secondary consequence no different from other undesirable, but unavoidable, side-effect of treatment[464] so not unlawful.[465] Where there is no therapeutic benefit the doctrine of double effect is inapplicable.[466] In *R v Bodkin Adams*, the doctor was found 'entitled to do all that was proper and necessary to relieve pain and suffering even if the measures he took might incidentally shorten life by hours or perhaps even longer'.[467] However, Dr Cox was guilty of attempted murder since the potassium chloride had no therapeutic value.[468] The patient's refusal to continue steroids exacerbated her pain but no argument regarding her responsibility was advanced.[469] The British Humanist Society considers it 'morally legitimate to give doses of pain-killers which are lethal...only if it is morally legitimate to kill that patient...in those

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[457]Wilson W, Smith KLM. The Doctors' Dilemma: Necessity and the Legality of Medical Intervention. *Med.Law International* 1995;**1**:387-410 at p391.
[458]Ibid, at p392.
[459]*Re A (Conjoined Twins)* op cit n445, at p99A per Brooke LJ.
[460]For instance, Israel: Eidelman AI. Care of Critically Ill Newborns. *J.Legal Med.* 1995;**16**:247-261,257.
[461]Wilson W, Smith KLM. The Doctors' Dilemma: Necessity and the Legality of Medical Intervention. *Med.Law International* 1995;**1**:387-410 at p398.
[462]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.
[463]*R v Bodkin Adams* [1957] Crim. LR 365. Under s23 Offences Against the Person Act 1861, it is a criminal offence to 'unlawfully administer to or cause to be administered to...any other person any poison or other destructive or noxious thing, so as to thereby endanger the life of such a person'.
[464]See: *Re C (A Minor)* [1989] 2 All ER 782 and *Airedale NHS Trust v Bland* [1993] AC 789 at p868 per Lord Goff. See also: House of Lords Select Committee on Medical Ethics Report 1993-4 HL21-I 1994 HMSO, London and *Government Response to the Report of the Select Committee on Medical Ethics* (Cmnd 2553) 1994 HMSO, London.
[465]*Airedale NHS Trust v Bland* [1993] AC 789 at p868 per Lord Goff.
[466]*Re A (Conjoined Twins)* op cit n462 at p56E per Ward LJ and p76A per Brooke LJ.
[467]*R v Bodkin Adams* [1957] Crim.LR 365.
[468]*R v Cox* 1992 12 BMLR 38.
[469]Dyer C. Rheumatologist convicted of attempted murder. *BMJ* 1993;**305**:371.

circumstances'.[470] Price argues that using the doctrine 'threatens analytical integrity'.[471] The key is the proportionality of the doctor's response. This is an area where further scientific research could clarify matters. The opportunity for euthanasia that presently exists would be removed making this a matter for legislators to address.

6.2.3.3 Criminal Intention

Withdrawing 'life support' can satisfy the mens rea of a murder charge.[472] Lord Browne-Wilkinson stated, 'where the accused was under a duty...to do the act he omitted to do such an omission can constitute the actus reus of homicide, either murder[473]...or manslaughter[474]...depending on the mens rea of the accused'.[475] By focusing upon the fact that the doctors were acting in the best interests of Bland, they could eschew intention to kill.[476] As Wilson and Smith point out, 'intention' in criminal law is equated with awareness that the outcome is 'virtually certain'.[477] The definitive statement is now found in *Woolin*.[478] The legitimacy of the doctor's actions is key to exonerating the doctor from blame. This suggests that where the patient is competent s/he should be involved in the decision unless treatment is clinically futile. For doctors to decide 'in the competent patient's best interests' is inappropriate. In such cases, the doctor could be held to have acted either negligently[479] or recklessly,[480] and be charged with manslaughter.[481] Regarding manslaughter, Lord Mackay explains that '(t)he ordinary principles of law on negligence apply to ascertain whether or not the defendant has been in breach of a duty of care towards the victim who died...the next question is whether that breach caused the death...if so...whether that breach should be characterized as gross negligence and therefore a crime'.[482] Using a test so protective of doctors as the *Bolam*[483] test to decide criminal liability is highly questionable.[484] Designating a patient not for resuscitation could be construed as intention that the patient should die. Therefore, the competent patient's agreement should be sought. If the patient is incompetent judicial approval seems necessary if treatment is not futile or clearly contrary to the patient's best interests. Also, although the issue has not been considered by the courts, where a doctor is treating an identifiable patient, if s/he withholds treatment on the grounds that other patients have a better call upon the scarce resources of the NHS, s/he is failing to act in the best interests of that patient who is the only one to whom a concrete duty of care is owed. Thus, government use of doctors as the primary agents of rationing exposes the medical profession to charges of criminal (and civil) liability.[485] To expect a doctor to consider 'future and contingent' patients, who may or may not materialise, at the time of treating the one to whom there is an immediate

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[470]In its evidence to the House of Lords Select Committee on Medical Ethics: Report 1993-4 HL21-I op cit n463 at para 76.
[471]Price D. Euthanasia, pain relief and double effect. *Legal Studies* 1997;**17**:323-342 at p325.
[472]As was argued by the Official Solicitor as guardian ad litem in *Airedale NHS Trust v Bland* [1993] AC 789 at pp835-855.
[473]*R v Gibbins* (1918) 13 Cr App R 134.
[474]*R v Stone and Dobinson* [1977] 1 QB 354.
[475]*Airedale NHS Trust v Bland* [1993] AC 789 at p881.
[476]A similar approach is taken in New Zealand: *Auckland Health Board v Attorney General of New Zealand.* (1993) 1 NZLR 235, at p253.
[477]Wilson W, Smith KLM. The Doctors' Dilemma: Necessity and the Legality of Medical Intervention. *Med.Law International* 1995;**1**:387-410 at p390.
[478]*R v Woolin* [1999] 1 AC 82 at pp96B-H per Lord Steyn.
[479]*R v Bateman* (1925) 19 Cr.App.R 8.
[480]*R v Stone and Dobinson* [1977] QB 354.
[481]*R v Lawrence* [1982] AC 510 and *R v Caldwell* [1982] AC 341 seemed to indicate that there was no longer a distinction to be drawn between reckless manslaughter and gross negligence manslaughter but *R v Adomako* [1994] 5 Med.LR 277 has reintroduced two separate types of involuntary manslaughter.
[482]*R v Adomako* [1994] 5 Med.LR 277 at p282.
[483]*Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582.
[484]Puxton M.Commentary [1994] 5 Med.LR 284.
[485]The situation described is differs from the practice of triage whereby a group of patients, all of whom are owed a concrete duty of care by the doctor or the hospital since they are present and together, are placed into order of priority of treatment. In such a case, the doctor's duty is owed equally to each patient and time of waiting in the queue is recognised as being secondary to urgency of treatment.

obligation is both unrealistic and dangerous for the medical profession.

The House of Lords, in *Bland*, rejected a defence of mercy killing.[486] McHale suggests '(i)t is possible that if the death appears to be a "mercy killing" by a relative then the prosecution may decide to accept a plea of manslaughter rather than prosecute for murder'.[487] If the relative denies causing death, charges of murder or attempted murder may be made. The courts show more leniency towards doctors who kill than relatives.[488] Over-zealousness in bringing criminal charges against over-burdened or compassionate carers should be avoided.

6.2.3.4 The Doctrine of Necessity

Re F[489] extended necessity to healthcare situations where the patient is incompetent.[490] Wilson and Smith suggest that doctors should have this defence available to them provided this is formulated with 'an articulated, principled, approach to fundamental patient rights of autonomy, and equal concern and respect'.[491] They believe that if doctors act in the patient's best clinical interests, they should not be held criminally culpable.[492] However, 'best interests' are not simply clinical interests.[493] The doctor's act/omission should only be considered absent criminal intent if the decision were made after due recognition, and balancing, of all the patient's interests. If there is doubt as to what constitutes a patient's 'best interests' independent arbitration seems proper.

Despite the House of Lords decision in *Dudley v Stephens*,[494] the Court of Appeal has now held necessity is an exceptional defence to murder.[495] As Smith predicted in 1989, 'it would not be too difficult'[496] to distinguish *Dudley v Stephens* in a case where '(t)he accident had chosen the unlucky' one.[497] It is subject to a test of proportionality.[498] The circumstances in which it is admissible are narrowly prescribed.[499] Sanctity of life and bodily integrity must sometimes give way where interests are closely entwined yet the welfare principle clearly shows one is to be preferenced.[500] However, just because necessity permits certain actions to be lawfully carried out that does not make them morally correct.[501] Any apparent similarities between separating conjoined twins and climbers cutting the rope between them become less persuasive once it is recognised that a degree of

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[486]*Airedale NHS Trust v Bland* [1993] AC 789 at p892 per Lord Mustill.
[487]McHale J, Fox M, Murphy J. *Health Care Law: Text and Materials* 1997 Sweet and Maxwell, London at p822.
[488]See, for example, the different sentences given to Julie Watts (who, if she removed the tube, did what could lawfully have been done by a doctor) and Dr Cox whose actions were clearly unlawful. The Court of Appeal eventually acquitted Julie Watts of the murder of her severely disabled 14 month old daughter. *Watts v R.* (unreported) 18 May 1998: Brooke C. My Agony, by Mother Cleared of Mercy Killing. *Daily Mail* 19 May 1998.
[489]*Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1.
[490]*Airedale NHS Trust v Bland* [1993] AC 789 at p892 per Lord Mustill.
[491]Wilson W, Smith KLM. The Doctors' Dilemma: Necessity and the Legality of Medical Intervention. *Med.Law International* 1995;1:387-410 at p406.
[492]Ibid.
[493]See the 'welfare checklist' found in the Children Act 1989 s1(3) regarding decisions on behalf of children.
[494]*Dudley v Stephens* (1884) 14 QBD 273. See also: Hanson N. *The Custom of the Sea.* 2000 Corgi Books, London.
[495]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1. The 'wholly exceptional' nature of the case is emphasised by Walker LJ at p118C.
[496]Smith JC. 'Necessity: Killing One that Others May Live' In *The Hamlyn Lectures: Justification and Excuse in the Criminal Law.* 1989 Stevens & Sons, London pp73-79 at p78.
[497]Ibid, at p79.
[498]*Re A (Conjoined Twins)* op cit n495, at p59G per Ward LJ; p96C per Brooke LJ and p113D per Walker LJ.
[499]Ibid, at p62B-C per Ward LJ and p99B-D per Brooke LJ.
[500]Ibid, at p99E per Brooke LJ.
[501]See for example, the House of Lords decision in *R v Bournewood Community and Mental Health Trust ex parte L* [1999] 1 AC 458 and the concerns of Lord Nolan (at p492) and Lord Steyn (at p 497).

consent to the climber's action exists.[502] The mountaineers have voluntarily and jointly embarked on a hazardous venture. Lord Steyn warns, '(t)he common law of necessity...places effective and unqualified control' in the hands of the doctors.[503] It is regrettable that a definitive statement on this defence and the impact of the Human Rights Act 1998 will not be forthcoming from the House of Lords. 'Advances in medical treatment...suggest that the criminal law's protection should be as wide as possible'.[504] Lord Hoffman believes that these 'fundamental and painful decisions about life and death' do not constitute an 'area in which any difference can be allowed to exist between what is legal and what is morally right'.[505]

6.3 Potential Impact of the Human Rights Act 1998

In *Coughlan,* the Court of Appeal, in partial justification, cited Article 8(1) European Convention on Human Rights in anticipation of the Human Rights Act 1998 (HRA) coming into force on 2 October 1998.[506] Claims can only be brought by victims against public authorities, bodies exercising duties of a public nature and their agents, not against private individuals.[507] Doctors are being warned that 'health professionals must be able to show that their decisions are compatible with the human rights set out in the Articles of the Convention'.[508] The right of children to make their own healthcare decisions will probably be enhanced.[509] In *Re MB*,[510] Butler-Sloss LJ pointed out that the right to respect for private and family life[511] is limited by pregnancy.[512] The right to life[513] does not extend to protecting the unborn child[514] because this prioritises the unborn child's over the mother's.[515] The 'repugnance' of the woman's decision in *St George's* did not alter the absence of foetal rights.[516] *St George's* emphasised the need to protect individuals from the 'coups d'etat' and 'gradual erosion' evident in other countries.[517] In America, the state's parens patriae role of protecting innocent third parties has been used to overrule refusals of Caesarian sections.[518] It is possible that, in any future case similar to St George's, the Human Rights Act 1998 could be interpreted as requiring that the needs of the unborn child are balanced against the wishes of the woman.

In *Re A (Conjoined Twins)* it was held that allowing the operation did not contravene Mary's right to life. [519] Wilson and Smith suggest that the 'doctrine of necessity which protects doctors when responsibly furthering

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[502]*Re A (Conjoined Twins)* op cit n495, at p112 per Walker LJ.
[503]*R v Bournewood Community and Mental Health Trust ex parte L* [1999] 1 AC 458 at p497 per Lord Steyn.
[504]*Re A (Conjoined Twins)* op cit n495, at p71A per Brooke LJ.
[505]*Airedale NHS Trust v Bland* [1993] AC 789 at p850.
[506]*R v North and East Devon HA, ex parte Coughlan* [2000] 2 WLR 622.
[507]Moraes FC. Making a Human Rights Claim. *NLJ* 2000:1485-6.
[508]Resuscitation Council (UK). Decisions Relating to Cardiopulmonary Resuscitation: *A Joint Statement from the British Medical Association, the Resuscitation Council (UK) and the Royal College of Nursing*. February 2001 Resuscitation Council (UK), London (www.resus.org.uk/pages/dnar.htm accessed 28 February 2001) 'Legal Issues' at p3. See also: British Medical Association. *The impact of the Human Rights Act 1998*. October 2000 BMA, London.
[509]Garwood Gowers A. Time for competent minors to have a legal right to self-determination with regard to medical intervention. Paper presented at 'Human Rights Act 1998 in Health Care Conference'. Nottingham Trent University, 10 May 2000.
[510]*Re MB (Medical Treatment)* [1997] 2 FLR 426 at p442.
[511]Article 8 of the European Convention on Human Rights.
[512]*Bruggemann and Scheuten v Federal Republic of Germany* [1977] 3 EHRR 244.
[513]Article 2 of the European Convention on Human Rights.
[514]Although the Commission has stated, but not elaborated, that, in 'certain circumstances', Article 2 might afford a foetus protection (*H v Norway* (1990)(No 17004/90, unreported). See Butler-Sloss LJ in *Re MB (Medical Treatment)* [1997] 2 FLR 426 at p445.
[515]*Paton v British Pregnancy Advisory Service Trustees* [1978] 2 All ER 987.
[516]*R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728 at p746. For a commentary see Bailey-Harris R. *LQR* 1998;**114**:550-555.
[517]*R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728 at p740 per Judge LJ.
[518]See: *Norwood Hospital v Munoz* (1991) 564 2d 1017 (Mass. Sup. Jud. Ct). However, Butler-Sloss LJ suggests, in *Re MB (Medical Treatment)* [1997] 2 FLR 426 at p444, that the American courts are moving towards the English position.
[519]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 at pp116-117 per Walker LJ.

the interests of the patients, is being subverted by a judicial unwillingness to look behind the practices of the medical profession to the rights-respecting traditions (respect for the sanctity of life and bodily integrity) which justify them'.[520] In *Re M* and *Re H*, heard after 2 October, it was held that decisions to withdraw treatment made in a patient's best interests and in accordance with a 'responsible body of medical opinion' do not constitute 'intentional deprivation of life' contrary to Article 2 of the European Convention on Human Rights.[521] The patients were alive within the meaning of Article 2 but there was no 'intention' to bring about the patients' deaths.[522] Article 3 did not apply because, even if their position could be described as 'degrading' or 'inhuman', the patients were unaware of it.[523] Withdrawal of treatment was 'in accordance with a responsible body of medical opinion'.[524] An omission to provide treatment could only be contrary to Article 2 if the state is under a positive obligation to safeguard life 'irrespective of the circumstances or prognosis'.[525] It is doubtful that 'families have any rights under Article 8 separate from the rights of the patient.[526] It is remotely possible that the contractual approach of *Saving Lives*[527] could be construed as containing enforceable obligations but it seems that the courts will be reluctant to hold that the HRA alters the existing position regarding the withholding or withdrawing of medical treatment. Indeed, *Re H* (1993) suggests that the courts should resist hearing cases requesting declarations as to lawfulness of treatment since this 'might be an unfortunate signal...that it was appropriate, as a matter of good medical practice, for the implementation of such procedures to be delayed pending the outcome of a costly application to court'.[528]

6.4 The Decision-making Process

6.4.1 Who Decides?

Parents are accorded the right of decision-making concerning the upbringing and healthcare of their (minor) child.[529] The rebuttable presumption is that such decisions are made in the child's 'best interests.[530] However, the assumption that they, by virtue of genetic ties, are best is inherently flawed.[531] This is evident when parents want life-saving treatment withheld because they do not wish to parent an 'abnormal' child[532] or believe the child cannot receive appropriate care and societal acceptance.[533] If parents withhold consent the doctor can override the refusal without obtaining court approval if the situation is desperate.[534] In other cases the parents' desire to save their child results in requests for burdensome treatment. Then the doctors' refusal to treat can

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[520]Wilson W, Smith KLM, op cit n491, at p402.
[521]*NHS Trust A v Mrs M and NHS Trust B v Mrs H* [2000] EWHC 29 (25 October 2000) para 30 per Dame Elizabeth Butler-Sloss P. Judgment available on www.bailii.org accessed 28 November 2000. Also reported in *The Times* 29 November 2000.
[522]Ibid, at para 18.
[523]Ibid, at para 49.
[524]Ibid.
[525]Ibid, at para 29.
[526]Ibid, at para 41.
[527]Department of Health. *Saving Lives: Our Healthier Nation* July 1999 The Stationery Office, London.
[528]*Re H (Mental Patient: Diagnosis)* [1993] 1 FLR 28 at p33 per Mr Nicholas Wilson QC sitting as deputy judge.
[529]Albeit of diminishing potency as explained by Balcombe LJ in *Re W (a minor) (medical treatment)* [1993] Fam 64, at p88.
[530]Hollen PJ, Brickle BB. Quality parental decision making and distress. *J.Paediatric Nursing* 1998;**13**,3:140-150.
[531]This tie was recognised by Waite LJ in *Re T (Wardship: Medical Treatment)* [1997] 1 FLR 502, at p514. It was accepted that the parents, at all times, were acting in the child's best interests. However, for a strong critique of the favouring of the parents as decision-makers in *Re T* and other cases, see Freeman, op cit n306 passim.
[532]For instance, see the parental rejection in *Re B (A Minor)(Wardship: Medical Treatment)* [1981] 1 WLR 1421. In other cases the parents may feel pressurised into taking on the role of carer. It is perhaps easier to explain that your child died rather than it is now the responsibility of the social services.
[533]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.
[534]See, for instance, the discussion concerning emergency treatment in *Re R (a minor) (blood transfusion)* [1993] 2 FLR 737, at p760 and the use of emergency protection powers in *Re O (A Minor)(Medical Treatment)* [1993] 2 FLR 149.

be 'based upon the best interests of the child and their own professional ethical integrity'[535] and is usually upheld.[536] Occasionally, doctors and families may agree but the decision may be referred to the courts by others who disagree.[537] Then, 'court must decide it'.[538] Rather than terminating, 'parental privileges' become 'subservient to the...welfare of the child'.[539]

Doctors can be seen as adopting 'ownership' of the decision dependent upon the health status of the patient. In *Re Dinnerstein* withholding resuscitation in the event of a cardiac arrest was a matter 'for the attending physician only'.[540] Jonsen suggests that the physician 'acquires a right over the disease and the patient by double title: he mixes his labor (sic) with the disease and masters it; he contracts with the patient to do his work...he almost has an independent right over the disease itself'.[541] 'Ownership' is evident in *Re A (Conjoined Twins)*: the court did not discuss whether Jodie's best interests required that the experienced Great Ormond Street team[542] did the separation rather than the inexperienced Manchester team.[543]

In *Re O*, parental rights were displaced short-term enabling blood transfusions to be given.[544] The judge expressed concern that even where the local authority has parental responsibility and can act alone, 'the ethics of (doctors) acting in reliance on the consent of only one of, say, three persons who hold parental responsibility and in opposition to the wishes of the other two' is debatable.[545] He advised that the courts should endeavour to hear both sides so genuine parental beliefs are treated respectfully.[546] An American court held that the decision 'should generally occur in the clinical setting', the role of the court being to 'assist...when an impasse is reached'.[547] *Re C* [1996] held that '(t)he courts do not instruct doctors how they should perform their clinical and professional duties...(but)...are ready to assist with the taking of responsibility in cases of grave anxiety'.[548]

The courts have yet to consider how far a person of 16 or 17 years who is themselves the parent of a child is able to give valid consent or refusal of treatment for that infant. Following *Re A (Conjoined Twins)* the scope for legitimate difference to tip the balance towards the parent as decision-maker as in *Re T*[549] seems substantially restricted.[550] It seems probable that doctors will accept decisions made by parents of any age where they agree with the medical team. Where there is scope for legitimate difference doctors, wishing to treat, will ask the court to decide. Decisions involving severely-handicapped neonates or terminally-ill children are rarely referred to the courts. Without an independent advisor, the child-parent is possibly more susceptible

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[535]Nelson LJ. Ethics and the provision of futile, harmful, or burdensome treatment to children. *Critical Care Medine*. 1992;**20**(3):427-433 at p229.

[536]See, for instance, *R v Secretary of State for Social Services, ex parte Walker* (1992) 3 BMLR 32; *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055 and *R v Portsmouth Hospitals NHS Trust ex parte Glass* [1999] 2 FLR 905.

[537]See, for instance, *In re B (A Minor) (Wardship: Medical Treatment)* 1981 1 WLR 1421 and *Re J (A Minor) (Child in Care: Medical Treatment)* [1993] Fam 15.

[538]*Re A (Conjoined Twins)* op cit n533, at p33D per Ward LJ.

[539]*Re K.D. (A Minor)(Ward: Termination of Access)* [1988] 1 AC 806, 825 per Lord Oliver of Aylmerton. Approved by Ward LJ in *Re A (Conjoined Twins)* op cit n533, at p50A.

[540]*Re Dinnerstein* (1978) 380 NE 2d 134 (App Ct Mass). Since this case was heard, Massachusetts, like most other states, now requires the physician to follow a strict protocol before writing a DNR order.

[541]Jonsen AR, *The New Medicine and The Old Ethics* 1990 Harvard University Press, London at p93.

[542]*Re A (Conjoined Twins)* op cit n533, at p63H per Brooke LJ.

[543]Ibid, at p67C per Brooke LJ.

[544]*Re O (A Minor) (Medical Treatment)* [1993] 2 FLR 149.

[545]Ibid, at p154.

[546]Ibid, at p155.

[547]*In re Joelle Rosebush*, 491 N. W.2d 633 (Mich. App. 1992). Lord Woolf MR takes a similar stance in *Rv Portsmouth NHS Trust, ex parte Glass* [1999] 2 FLR 905 at p908.

[548]*Re C (A Baby)* [1996] 2 FLR 43, at p44 per Sir Stephen Brown P.

[549]*Re T (Wardship: Medical Treatment)* [1997] 1 WLR 242.

[550]*Re A (Conjoined Twins)* op cit n533, Section IV Family Law para 9.2 at pp51C-52C per Ward LJ.

to manipulation by the medical profession whom, as shown in earlier chapters, consider this acceptable practice. Consequently, it may be inappropriate to maintain the normal exclusivity of decision-making. However, it would be inappropriate for the child-parent to be denied decision-making capacity regarding the infant in the absence of evidence that the child-parent cannot decide appropriately.[551] Wilson J. is correct in holding that 'the law must at the very least be clear before it should be so construed as to permit invasion of parental autonomy by public authorities'.[552] Yet, the lack of clarity in the law did not tempt the Court of Appeal to leave decision-making to the parents in *Re A (Conjoined Twins)*.[553]

The British legislature is currently reviewing these issues.[554] Browne-Wilkinson LJ questioned whether judges should 'seek to develop new law' or whether it is for society 'through the democratic expression of its views in Parliament, to reach its decisions on the underlying moral and practical problems and then reflect those decisions in legislation?'[555] The guardian ad litem in *Bland* argued that 'the question of life as against death is one wholly outside the competence of judicial determination...since 'the court is unable to evaluate the consequence of death'.[556] The Court of Appeal was the decision-maker in *Re A (Conjoined Twins)* despite the fact that it is 'a court of law, not of morals'.[557] It is highly questionable whether cases raising such complex ethical concerns should be decided in a court of law. Legislative change can restrict the need for judicial intervention.[558] Most American states now recognise Advance Directives.[559] English decisions indicate that doctors following Advance Directives in good faith will not be liable to prosecution.[560] This suggests both that wishes of previously autonomous patients are important and that the courts do not wish to interfere with well-balanced patient-doctor relationships. In *Re A (Conjoined Twins)* the lack of legal precedent regarding conjoined twins was attributed to the role of ethics committees as decision-makers in the U.S.A.[561] Since the court 'is not equipped to choose between...competing philosophies'[562] perhaps it should not be the arbitrator. As already noted, the court is 'a court of law' so legal principles are determinative with medical criteria seeming more persuasive regarding 'best interests' than ethics.[563] Whilst 'patients do not know as much medicine as their doctors, patients know as much and more about their own values and interests'.[564] Judges frequently fail to critique medical evidence so too narrow a view is taken of highly complex issues.[565] Although medical advances create these situations the dominant perspective need not be either medical or legal. Such cases could be decided in a different forum if the legislature so wished.

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[551]For example, given the policy of encouraging childhood immunisation, it would be burdensome to insist the child-parent could not consent for her baby to be vaccinated. However, if the child-parent refused immunisation, that could be interpreted as evidence that she lacked capacity. Whether this could seen to be sufficiently against the baby's best interests to warrant referral to the courts is debatable.

[552]*In Re X (Minors)(Care Proceedings: Parental Responsibility)* [2000] WLR 1031 at p1035

[553]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.

[554]Lord Chancellor's Department. *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults.* (Cm 3803) December 1997 The Stationery Office, London and *Making Decisions: the Government's proposals for making decisions on behalf of mentally incapacitated adults.* (Cm 4465) 1999 The Stationery Office, London. These will be examined in the next chapter.

[555]*Airedale NHS Trust v Bland* [1993] AC 789 at p878.

[556]Ibid, at 837.

[557]*Re A (Conjoined Twins)* op cit n553, at p6H per Ward LJ. See also, *Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389 at p401B per Dame Elizabeth Butler-Sloss P.

[558]As called for by Lord Browne-Wilkinson in *Airedale NHS Trust v Bland* [1993] AC 789 at p878.

[559]Annas GJ: The Healthcare Proxy and the Living Will. *New Eng.J Med* April 25 1991 1210 at p1210 reporting the effect of the Omnibus Reconciliation Act 1990 Pub L No 101-508 paras 4206 and 4751.

[560]*Re C (Adult: Refusal of Medical Treatment)* [1994] 1 FLR 31.

[561]*Re A (Conjoined Twins)* op cit n553, at p66H per Brooke LJ. A similar (36 hours long) operation to separate conjoined twins was carried out the weekend of 30 September - 1 October 2000 in the USA following approval from the hospital ethics committee, not a court: personal communication.

[562]Ibid, at p98F per Brooke LJ.

[563]Ibid, at p6H per Ward LJ.

[564]Jonsen AR, *The New Medicine and The Old Ethics* 1990 Harvard University Press, London at pp96-97.

[565]Finnis JM. Bland: Crossing the Rubicon? *Law Quarterly Review* 1993;**109:**329-337 at p334.

6.4.2 What values are important?

Autonomy is given great support. The right of competent patients to refuse treatment and the right of doctors not to give treatment contrary to their consciences is upheld.[566] Doctors and judges must use a rational process.[567] Yet, in the interests of 'autonomy', judges support irrational refusals of treatment thereby failing to protect the weakest.[568] However, the principle of 'non-abandonment' creates obligations.[569] Perhaps the slow death mandated in *Bland* and other cases is judicial approval of doctor abandonment[570] despite the manipulation regarding patient autonomy in Bland to justify allowing 'dignified' death.[571]

The judiciary are reluctant to place sanctity of life before quality or the patient's right of self-determination. According to Finnis, the judiciary, in *Bland*, redefined human life.[572] Consequently, even those with personhood can now be 'abandoned'.[573] The courts distinguish causing death from preventing its natural occurrence but the doctrine of necessity now allows positive acts of medical killing to occur albeit in restricted circumstances.[574] With patients like *J*, there seems no reason to preserve life[575] but 'little C' had 'personhood'[576] like David Glass.[577] The decision in *Re T* may have been based less on 'best interests' than a belief that societal resources should not be used for rescue attempts that there is no duty to perform.[578] There appears to be tacit support for the notion that 'those who sap the strength of the state' can be 'sacrificed'.[579] Lord Goff held the court's role is not to ensure fair access to treatment, merely to decide if non-treatment is 'in accordance with a respectable body of medical opinion and that it is reasonable'.[580] Keeping certain patients alive seems potentially harmful to society, through bringing the use of medical technology into disrepute or creating an unjust burden on resources, so decisions allowing death are made.[581] The autonomy of incompetents is little respected when their tissue can save others.[582] Such decisions suggest that if people are of little value in themselves, their existence is validated by making use of them. Dressing decisions in a 'best interests' framework hides any contentious belief that society has a legitimate interest in maximising the contribution of each individual.

Keyserlinck, like Keown[583], argues that the real issue is not the value of life but the value of treatment.[584] However, the decision often focuses upon the value of the patient's life because of the emphasis placed upon

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[566]See: *In re J (A Minor)(Child in Care: Medical Treatment)* [1993] Fam.15 and *Airedale NHS Trust v Bland* [1993] AC 789 at p896 per Lord Mustill.
[567]*Re A (Conjoined Twins)* op cit n553, at p60C-E per Ward LJ.
[568]*R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728.
[569]Quinn TE, Cassel CK. Non-abandonment: A Central Obligation for Physicians *Trends in Healthcare, Law and Ethics* 1995;**10**,1-2:25-32. See discussion earlier in this thesis.
[570]*Airedale NHS Trust v Bland* [1993] AC 789.
[571]See the argument of Anthony Lester QC and Pushpinder Saini as amicus curiae in *Airedale NHS Trust v Bland* [1993] AC 789 at pp848-850 adopted by Lord Goff at pp864-5.
[572]Finnis JM. Bland: Crossing the Rubicon? *Law Quarterly Review* 1993;**109:**329-337 at p334.
[573]See *Re C (Medical Treatment)* [1998] 1 FLR 384.
[574]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.
[575]*Re J (A Minor) (Child in Care: Medical Treatment)* [1993] Fam 15.
[576]*Re C (A Minor) (Medical Treatment)* [1998] 1 FLR 384.
[577]*Rv Portsmouth NHS Trust ex parte Glass* [1999] 2 FLR 905.
[578]*Re T (Wardship: Medical Treatment)* [1997] 1 FLR 502.
[579]*Buck v Bell* 274 US 200 (1927) per Holmes J.
[580]*Airedale NHS Trust v Bland* [1993] AC 789 at p884 per Lord Browne-Wilkinson.
[581]As possible, very tragic, examples, see the case of the patient with the skin deformity described by one consultant and the boy with 90% burns described by another.
[582]See, for instance, *Re Y (Mental Incapacity: Bone Marrow Transplant)* [1997] 2 WLR 556.
[583]Keown, J. Restoring Moral and Intellectual Shape to the Law after Bland(1997) 113 L.Q.R. 481.
[584]Keyserlinck, op cit n354 at pp55-6.

(predominantly medical) estimations of the patient's present and future quality of life. Lord Goff, in *Bland*[585], was unhappy at the emphasis placed on quality of life in *Re J.*[586] Lord Mustill firmly rejected the argument that the 'interest of the state in preserving life' can be reduced where the 'quality of the life is diminished by disease or incapacity' since this would lead to active euthanasia.[587] The fact that few applications regarding patients in a vegetative state have been made suggests that neither society in general nor all doctors believe continued treatment is not in the patient's best interests.

6.5 Conclusion

Openness of decision-making and procedure is seen as increasingly necessary by the courts. Blanket bans on treatment are not deemed acceptable so doctors and healthcare commissioners (purchasers) learn new phraseology to cover true intent. In line with emphasis on open government and transparency of decision-making by public bodies medical decision-making needs to follow a similar approach.

The case law tells doctors that patient autonomy is important. However, this message is weakened by the courts allowing doctors to not only decide whether a patient is autonomous but then what constitutes the best interests of an incompetent patient. The empirical evidence obtained for this thesis indicates that the legal and ethical understanding of doctors is limited and their desire to retain control strong. The case law indicates that in deciding 'best interests' the burden on relatives can be considered, even at the expense of the patient's best interests, and that guidelines, albeit produced by a 'responsible body of medical opinion', can be ignored. Sanctity of life has little importance and the doctor's interpretation of the patient's quality of life is decisive. The judicial distortions of 'best interests' have become so much a matter of course that even where it would be possible to hold that the right of healthcare staff not to be assaulted prevailed over a patient's right to treatment, the courts have preferred to misuse the 'best interests' principle. Doctors learn that as long as they employ certain key words, (necessary, futility, unacceptable quality of life, best interests, guidelines, clinical judgment, experience) there is no effective challenge once their decision is made. 'Mutual understanding between the doctors and the judges' may be the 'best way to ensure the evolution of a sensitive and sensible legal framework for the treatment and care of patients' but the tendency of the judiciary to defer to the medics fails to protect patients.[588] Therefore, the inquisitorial approach taken in *Re A (Conjoined Twins)* is welcome. Law alone 'cannot effect a substantial change in the routine behaviour of doctors, but it can have some symbolic impact on their perception of what is appropriate in relationships with patients'.[589] 'The focus of judicial decisions...(is)...to rein in excessive medical enthusiasm'.[590]

The contention that 'the decision to treat or not to treat will be determined only upon clinical grounds; that no patient shall be treated as a vehicle for social policy, and that all patients are accorded the same social worth'[591] receives little real support. Patients do not receive equal protection or have equal social worth. Incompetent

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[585] *Airedale NHS Trust v Bland* [1993] AC 789 at p869.
[586] *In re J (A Minor)(Wardship: Medical Treatment)* [1991] Fam.33 at p55.
[587] *Airedale NHS Trust v Bland* [1993] AC 789 at p894.
[588] *Airedale NHS Trust v Bland* [1993] AC 789 at p871 per Lord Goff of Chievely.
[589] Teff H. *Reasonable Care: Legal Perspectives on the Doctor-Patient Relationship.* 1994 Clarendon Press, Oxford at p238.
[590] *Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389 at p397G per Dame Elizabeth Butler-Sloss P.
[591] Wilson W, Smith KLM. The Doctors' Dilemma: Necessity and the Legality of Medical Intervention. *Med.Law International* 1995;**1**:387-410 at p400.

patients need more protection than currently received since there is potential for abuse (intentional or otherwise) particularly when non-therapeutic treatment is proposed.[592] The courts are better able to consider and balance all the factors relating to a person's welfare than even the most experienced doctors because these decisions have to balance public as well as private interests.[593] Theoretically, the court's sole focus is the individual patient whereas doctors, with little formal training in decision-making, have to balance individual interests against those of other patients.[594] The feasibility of doctors switching from a model of decision-making legitimating the interests of others to one concentrating on the 'best interests of this individual alone' is questionable. Tomlinson argues that if doctors can lawfully restrict the treatments offered patients it can only be because they have the 'authority to act on judgements of value'.[595] This authority can only exist provided society accepts it is proper. Society seems less ready to accept this premise.

Little has changed since Brazier wrote: 'the law as it affects sensitive health care decisions is frequently ill-defined...(and) can offer the doctor and his patient little clear guidance as to their rights and obligations to each other and to the community'.[596] Quality decision-making needs improved communication between doctors and patients, particularly regarding treatment risks,[597] and improved understanding of the decision-making process.[598] This requires both sides to develop the skills necessary.[599] Promoting Advance Directives could assist. It should be possible for doctors, patient groups, lawyers and ethicists to work together to produce a set of instructions covering the most-feared conditions. Necessity is increasingly used as 'gap-filler' to mend out-dated legislation[600] or cover the void between medical opinion and precedent case law.[601] Law is being shaped by medical ethics. 'Necessity' becomes the language of the 'responsible body of medical opinion'. The lack of a more appropriate forum for resolving issues of medical advances straining the boundaries of law and ethics has resulted in the intrinsic worth of human lives spiralling downwards like sycamore seeds in the wind: law one side, medicine the other, key words flying around, and ethics desperately trying to maintain a grip.

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[592]The Rt Hon Sir John Balcombe. The Child, the Doctor and the Judge *J.Roy.Soc.Med.* 1996; **89,**28:3-9 at p9.
[593]Per Lord Griffiths in *Re F (Mental Patient: Sterilisation)* [1990] 2 AC 1 at p70. See also, p41E and p42B per Butler-SlossLJ.
[594]See, for instance, the burden placed on doctors to consider the welfare of any child who would be born as a result of giving infertility treatment before accepting the patient for IVF treatment as shown in *R v Ethical Committee of St Mary's Hospital (Manchester) ex parte H* [1988] 1 FLR 512.
[595]Tomlinson T, Brody H. Futility and the ethics of resuscitation. *JAMA* 1990; **264:**1276-1280 at p1277.
[596]Brazier M. *Medicine, Patients and the Law.* 1987 Penguin Books Ltd, Harmonsworth at p325.
[597]Horton R. Commentary: How should doctors respond to the GMC's judgments on Bristol? *The Lancet* 1998; **351:**1900-1901.
[598]Walton DN, Donen N. Ethical Decision Making and the Critical Care Team. *Critical Care Clinics* 1986;**2,**1:101-109.
[599]See: Campbell AGM, McHaffie HE. Prolonging life and allowing death: infants. *J.Med.Ethics* 1995;**21:**339-344 at pp341-2 and Craig VJ. Patient decision-making: medical ethics and mediation. *J. Med.Ethics* 1996;**22:**164-7.
[600]*Re F (Adult: Court's Jurisdiction)* [2000] 2 FLR 512.
[601]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.

CHAPTER SEVEN

CURRENT REFORM PROPOSALS

This chapter, and the next, explore how the decision-making process can be improved. In this chapter the views of the consultants on how to improve decision-making will be examined first, since their support is necessary for reforms to work. Then different proposals which have been made since the empirical research for this thesis was carried out will be critiqued to see if they resolve the difficulties identified. These difficulties include the questions of which inputs to the decision-making process are acceptable and when non-treatment decisions require scrutiny outside the medical domain.

7.1 The Doctors' Views

The eighty-five consultants were asked:

How do you feel decision-making regarding allocation of resources could be improved? Do you feel there is a place for local population involvement?

How can the process of making decisions about individual patients be improved? Should there be national guidelines?

7.1.1 Decision-making at the societal level

7.1.1.1 Government guidelines

The last government explained that 'guidance is stronger than guidelines...if an authority did not take notice of guidance, the Secretary of State has the power to make directions...guidance is expected to be followed'.[1] Government medication 'blacklists' mean some treatments are openly withheld but most restrictions on treatment are achieved through less direct means. Purchasing bodies are used to deflect criticism from governments. Some identify closely with government strategies in the exercise of their discretion.[2] Doctors felt the resource allocation process needed to be more open:

> *It should be simplified, clarified and made more transparent.* C12

> *It could be more explicit.* A17

Most of the consultants would welcome national debate about resource allocation:

> *It's a discussion for society. It's too complex for doctors.* B17

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[1]Jacob JM. Lawyers go to hospital. 1991 *Public Law* 255-281 at p266.
[2]For instance, see the decision of the purchasing body in *R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.

Someone's got to take the lead and decide what we can and cannot afford. A24

Some sort of national guideline and consensus is desperately needed. C9

It's more difficult with these minority services (dialysis) to have a local plan - it needs to be a much bigger, global, national planning with national guidance as to what the level of funding should be and what resources should be in any one unit and working out if you have the right number of units for the population. A36

Guidelines and policies can be manipulated as a way to reduce healthcare costs by withholding or withdrawing treatment sooner rather than later.[3] Views amongst consultants varied as to whether more money was the answer:

Health authorities need more money. B11

Just putting more money into the system isn't going to solve anything...Diseases and treatments will have to be looked at in a more effective way, looking at outcomes. A18

Exponential growth in medical technology occurred at the same time financial restrictions were being introduced. Some specialties have always had to justify expenditure:

I was chairman of the national working party...a specialty that didn't exist twenty years ago...right from the beginning we had to look at cost-effectiveness and have had to deal with those arguments in terms of introducing restraint. C14

7.1.1.2 Improving the resource allocation process

Medical decision-making can be formally or informally regulated.[4] Apart from contentious issues like abortion and surrogacy, the U.K. has taken a laissez-faire approach but increasing litigation, complaints and healthcare costs mean ways to restrict clinical freedom are being sought.[5] Some doctors see legislation as a way to resolve wastage of resources.[6] The issue of rationing on the grounds of age was mentioned by only three consultants despite recent media and journalistic coverage of the 'fair innings' argument:

I refuse to make choices on age but other people would be happy saying the young and mothers should be guaranteed rights to treatments before others. B18

We're seeing more elderly people being admitted to hospital with terminal illnesses...the problem is

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[3]Some American doctors already believe that DNAR policies can be legitimately used to control the cost of health care: Murphy DJ; Finucane TE. New Do-Not-Resuscitate Policies. *Arch.Intern.Med.*1993;**153:**1641-8.

[4]For a comprehensive analysis see: Moran M, Wood B. *States, regulation and the medical profession.* 1993 Oxford University Press, London, in particular, at pp90-111.

[5]Occasionally, Parliament has called for national guidelines to be developed by healthcare professions: MPs demand guidelines on life-saving bids. *Hospital Doctor* 21 November 1991 p2. See also: Department of Health. *A First Class Service: Quality in the NHS* June 1998 The Stationery Office, London paras 2.13, 2.17 and Lawrence H. 'Postcode' prescribing. *Healthcare Parliamentary Monitor* 22 March 1999, at p3.

[6]Rogers L. Doctors seek £50 fine for patients who fail to show. *Sunday Times* 29 June 1997. Call for patients to be charged £5 for visits to GP. *The Times* 20 January 1999.

that we can now treat some of those conditions. A26

The fair innings argument does have merit. A5

Healthcare is dominated by expensive treatments due to the lack of independent research.[7] Relatively inexpensive 'treatments' such as influenza vaccination might carry hidden costs in preventing the death of non-income-generating persons.[8] Research might reveal unsuspected side-effects associated with conventional treatments and the acceptability of continued use would have to be decided.[9] Audit[10] can identify patterns and, combined with algorithms or flow charts, might help identify treatment options, but acceptable and accurate predictors of outcomes are difficult to establish.[11] Scope exists for computer-assisted diagnosis[12] which could be manipulated to identify only certain, cost-effective treatment options thereby increasing uniformity. However, '(i)f medical research is to be at the service of knowledge, it is also to be at the service of society in order to help mankind to progress, both economically and socially.'[13] As patients become more knowledgeable, demands for 'the best' will grow:

The public's opinions tend to be swayed a lot by the media, by emotion. C10

Identifying a national level of healthcare provision to provide a baseline could help to eliminate geographical variation. However, baselines can be interpreted as equalising distribution of healthcare resources, or maximising collective health status, not necessarily prioritising those whose need is greatest. Two of the consultants believed it was necessary to remove the barriers between healthcare and social care:

The social services are split from the NHS and every time (this district) has lost. D13

There needs to be improving dialogue. A4

Many of the consultants felt a national policy was needed across the country to eliminate rationing 'by postcode[14] and increasing regional inequality[15]:

You can make a very strong case for a national policy, particularly on these various expensive

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[7]For instance, see the patenting of human genetic codes as the Human Genome is mapped: Terry L, Cedar S. Nursing and the 'New Genetics'. *Nursing Standard* (scheduled for publication 28 March 2001 - accepted for publication 4 December 2000).

[8]This is acknowledged as a very cynical argument.

[9]For instance, recent research indicates that children born as a result of in-vitro-fertilisation treatment are more likely to suffer from hearing and speech difficulties or have retarded mental development than those conceived naturally: te Velde et al; Commentary: Concerns about assisted reproduction. *The Lancet* 1998; **351:**1524-5. See also, Pritchard KI. Commentary: Is tamoxifen effective in prevention of breast cancer? *The Lancet* 1998; **352:** 80-81, 93, 98.

[10]Audit is defined as 'the systematic critical analysis of the quality of medical care, including the procedures used for diagnosis and the treatment, the use of resources, and the resulting outcome and quality of life for the patient': Department of Health. *NHS Review Working Paper No 6*, 1989 Department.of Health, London.

[11]See: McIntyre KM, Failure of 'Predictors' of Cardiopulmonary Resuscitation Outcomes to Predict Cardiopulmonary Resuscitation Outcomes. *Arch.Intern.Med.* 1993:**153:**1293-6 and Stewart K et al. Does audit improve DNR decision making? *J.Roy.Coll.Physic.*1994;**28,**4:318-321. See also, as evidence of the medical professions' unwillingness to accept audit: Stewart K et al. Does audit improve DNR decision making? *J.Roy.Coll.Physic.*1994;**28,**4:318-321 at p321; Martin LF et al. The Surgeon's Role in improving Medical Care. *American J. Surgery* 1997;**174:**294-296, in particular, pp295-6 and Department of Health *Primary Care: Delivering the Future* 1996 The Stationery Office, London at para 3.4.

[12]Fox J. 'Formal and knowledge-based methods in decision technology'. In Dowie J, Elstein A (Eds) *Professional judgment - a reader in clinical decision-making.* 1988 Cambridge University Press, Cambridge at pp226-252.

[13]Pompidou A. Research in medical ethics and ethics of research in the European Union. *Biomedical Health Research* 1995;**6,**2:8-9 at p9.

[14]They are joined in this call by others. See: Light DW. The real ethics of rationing. *BMJ* 1997;**315:**112-5 and BMJ Editorial. At last, a public health minister. *BMJ* 1997;**314:**1498-9.

[15]Joseph Rowntree Foundation. *Death in Britain: How Local Mortality Rates have Changed.* 1997 York Publishing Services, York.

treatments such as bone marrow transplantations, chemotherapy and some of the new anti-cancer drugs. C6

There aren't a great deal of various specific guidelines for the national budgets...they have to be evidence-based now and if the evidence isn't there...you could have a sort of filling-in by an expert body. D3

Some of the consultants felt the NHS was manipulated for political reasons:

I do not believe local health authorities have the resources or the expertise to make a full range of purchasing decisions...it is essentially a political cop-out to pretend you can devolve purchasing decisions which affect a national service from the centre to health authorities...I would favour the a-political solution of a national health commission which is charged with establishing the basic priorities. B16

Take health out of the political agenda. B15

Eddy argues for patient representatives to replace government bodies in determining available treatments.[16] Lay input is valued by the present government but the Oregon model was only mentioned by four consultants and views varied:

I'm not impressed. C16

I think it's based on very sad principles. A15

Like the Oregon experiments...we need to have three areas of dialogue (with medical experts, health authorities and the public). C5

I thought it was brilliant. It was just that people didn't like the conclusions. A1

Pessimism and anxiety was expressed by some of the consultants interviewed:

I don't think you can improve decision-making - there will always be pressure groups. B3

7.1.1.3 Who should be involved

Greater local input can help identify specific needs particularly if the process accesses those often excluded from formal consultations. However, the majority of consultants rejected local population involvement and there was evidence of anxiety regarding pressure groups. The underlying assumption seemed to be that lay input would be 'unbalanced':

The public would be influenced by pressure groups. C8

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[16]Eddy DM. Connecting Value and Costs: whom do we ask and what do we ask them? *JAMA* 1990;**264**,13:1737-9.

Local population...you will find a small number of activists leading the argument. The majority of the population would prefer to leave it to a professional body they trust and on the whole, they trust the medical professional. A23

Local population should have more of a say in what they want from their local hospital. A35

Likewise, Community Health Councils were not seen as an appropriate way to input local views:

CHCs are run by people who seem to have personal axes to grind...their fostering complaints and encouraging litigation forces staff to take a defensive stance. D1

There was strong support amongst interviewees for the idea of increased input from General Practitioners:

You need to talk to chief GPs...I don't think you should ask the patients as they don't have a clue. A32

GPs are more in touch with their patients and actually make more sensible decisions regarding priorities than the health authority. B19

Decisions...should be more directly involved with the people who are providing that care. B14

The approval of local input via medical professionals starkly contrasted with the rejection of lay input. This can be interpreted as evidence of the desire of professions to maintain control over their domain although several foresaw problems in placing resource allocation solely in the hands of doctors:

Doctors would order the earth if they could. Doctors and administrators are still the best mechanism. C13

At the moment it is largely done by civil servants...There has to be more public accountability...more involvement of patient groups, family practitioners in particular and hospital specialists. A14

7.1.2 Decision-making at the individual patient level

7.1.2.1 Medical Guidelines

Stoll wants national and international guidelines and standards because there are 'marked differences between institutions in the use of aggressive or high tech (sic) procedures'.[17] Haycox warns that 'guidelines must start from a patient perspective whilst encompassing the needs of the whole community'.[18] The Clinical Standards Advisory Group mirrors the work done in the U.S.A. where the 'development, implementation and monitoring of guidelines is overseen by custom built organisations'.[19] However, it is recognised in the U.S.A. that although

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[17]Stoll BA. *Ethical Dilemmas in Cancer Care.* 1989 The MacMillan Press Ltd., Basingstoke at p23.
[18]Haycox A, et al. Clinical guidelines - the hidden costs. *BMJ* 1999;**318:**391-393 at p393.
[19]Editorial BMJ. Clinical Guidelines *BMJ* 1997;**315:**324.

guidelines 'might be based on rational economic and research-based considerations' they can 'lack the crucial input of doctors with a day-to-day concern for the welfare of individual patients'.[20] Linked with clinical audit, the way ahead is clearly prescriptive. One danger of guidelines is that they can encourage new treatments or new decision-making methodologies being adopted when 'in practice their results may be poorer than expected'.[21] Opinion was divided over their usefulness. The number of consultants supporting national guidelines was exactly the same as the number opposing them. However, support was almost always qualified whereas opposition was very powerfully expressed without qualification.

Typical remarks supporting national guidelines were:

> *Certainly in the case of cancer...for other diseases it is more difficult...the best way is to get a multi-disciplinary team together.* D12

> *I've been involved in drawing up national (clinical) guidelines...but when it comes to guidelines for ethical issues I think that's a lot harder...they would probably be rather philosophical.* A14

> *As long as one understands what their limitations are, that you're always going to have people who are exceptions...they're helpful.* C4

The absence of guidelines could lead to inappropriate practice being adopted as normal by younger colleagues.[22] Those supporting them often perceived guidelines as more useful for less-experienced staff than themselves, experienced consultants :

> *You need to have some sort of policies and guidelines for junior staff and nursing staff.* A12

Guidelines could be seen as a way to control mavericks:

> *You can have guidelines that stop politicians withholding treatment; you can have guidelines that stop doctors treating - there are some gung-ho surgeons.* B9

Typical reasons for rejecting guidelines for clinical decisions were that patients and circumstances are unique and guidelines would ignore this individuality.

> *Everyone's an individual...national guidelines - No.* B6

> *There is a danger in guidelines...we have to look at individual babies...they're not specific...either they will be too open-ended so they won't be as much use, or they risk being too closed.* A7

> *Everyone told her she was too young to have a hysterectomy and she said to me, well, how old do I*

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[20]Prof Ted Marmor in: *Health Care Resources, Choices and Decisions. St Catherine's Conference Report No37* 1993. The King George VI and Queen Elizabeth Foundation of St Catherine's, Windsor, at p10.
[21]Haycox et al, op cit n18 at p91.
[22]For instance, see Stuttaford T. Shifting views on Euthanasia. *The Times* 6 January 1999 p2 in response to front page article: Horsnell M. Police check hospitals over 'backdoor euthanasia' *The Times* 6 January 1999.

have to be?...That's the sort of thing we can't have written down. A25[23]

In the few (cases) where decisions are not straightforward, they're so highly specific and individual that guidelines are unhelpful. C3

Our Royal College has guidelines...they ended up being a good small textbook almost entirely inapplicable to an individual situation. C7

Sometimes, the reason for rejecting guidelines was based on the difficulty of who should draft them:

Guidelines are produced by old men who've usually long since finished practising at the coalface...An example is the national guidelines for hip replacement...this report came from the Royal College of Physicians - people who break their hip aren't treated by physicians. A23

Even experts don't agree. C10

One consultant suggested a collegiate approach to decision-making as an alternative to guidelines:

Who would be responsible for drawing them up? Would it be managers, ...government employees,...patient advocacy groups,...lawyers?...If it's the wish of three consultants in a hospital then management should not restrict that patient. B9

Sometimes the reason given for rejection seemed based on flawed ethical reasoning:

We must get (emotionally) involved...all my patients have access to the mother, father, brother, sister, child role as I try to do for them what I would do for my family member...Guidelines would give the objectivity...but...make it impersonal. B4

Resistance on the grounds that guidelines fail to meet individual needs might be misplaced. Setting out a structure for decision-making could help meet the needs of patients, family and other professionals:

The national guidelines in psychiatry had a lot of resistance initially but it really has sensitised us to patient and relatives' needs and made us work more cohesively and improved communication. A28

We are quite used to thinking we need the social worker, the psychologist, the key nurses...(Others) don't always remember to involve all those upon whom (the decision) has impact. So guidelines on structure might be useful. A36

Failure to comply with guidelines may be evidence of a breach of the standard of care.[24] Eventually 'the time may come...when a new recommendation may be so well proved...it should be adopted' thus obliging doctors

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[23]Recounting how he was persuaded to carry out a hysterectomy in a 'girl' under 25 years old.
[24]Harpwood V. NHS Reform, Audit, Protocols and Standards of Care. *Med.Law.Intern.* 1994; 1:241-259.

to modify their practice accordingly.[25] There was much more support for flexible guidance but confusion over terminology was evident[26]:

> *There are more factors that can be inherently included in a simple algorithm or simple protocol.* D6

> *As long as they are guidelines not rigid protocols.* A8

> *They start off being guidelines then become more and more rigid...you (should) employ intelligent people who will make an appropriate decision within a flexible framework.* A34

> *Some treatments are nationally protocoled and the individual consultants can alter them as the situation may dictate.* C12

The NHS Executive states that guidelines should produce 'improvements in health' at 'acceptable costs'.[27] The 'desirable attributes' of guidelines include: validity; cost-effectiveness; reproducibility; reliability; representative development; clinical applicability; clinical flexibility; clarity; meticulous documentation; scheduled review and utilisation review.[28] Doctors are stigmatised as 'spendthrifts' but receive little guidance on how to allocate resources.[29] As medicine advances, it becomes harder to develop guidelines which reject less viable cases hence healthcare costs can escalate as doctors use guidelines as a way to 'prove' treatment is appropriate.[30] Several consultants linked guidelines for individual decision-making with resource allocation suggesting that treatment decisions and costs are combined in their minds:

> *There is a place if you are taking on board the resource implication...helpful assuming it reflects public opinion, to give some idea of the value that society puts on different treatments and their costs.* B1

> *I broadly agree with the guidelines[31]...but they haven't really grasped the issue of economics...they have to decide what level of problem it is not economically justifiable to treat because it takes away resources from other perfectly treatable children.* C9

> *The problem with guidelines and recommendations is that they tend to push healthcare costs up...there will be more tests, more treatment, more interventions...the NHS is cheap because we employ doctors to be ignorant.* A13

> *The management still want doctors to make decisions about who to treat and who and when not to treat because it gets them out of a sticky corner and they always say the resource is there - it's a*

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[25] *Crawford v Board of Governors of Charing Cross Hospital.* (Unreported) *The Times* 8 December 1953 per Denning J.
[26] This is a similar finding to Harpwood: Harpwood V. Guidelines in medical practice: the legal issues. *Cephalagia* 1998 Supp 21:56-62 at p56.
[27] NHSE. *Effective Health Care* 1995 para 6:1 "Clinical practice guidelines in a purchasing environment." NHSE, Leeds.
[28] Ibid.
[29] See, Martin LF. The Surgeon's Role in Improving Medical Care. *American J.Surgery* 1997, **174**:294-6 and Cook D et al. Determinants in Canadian Health Care Workers of the Decision to Withdraw Life Support From the Critically Ill. *JAMA* 1995; **273**,9:703-708, in particular, at p708.
[30] For instance, see Roberton's challenge to the government to ensure sufficient funding to treat babies between 500-800 grams: Roberton NRC. Should we look after babies less than 800g? *Arch.Dis.Childhood* 1993;**68**:326-9 at p329.
[31] Royal College of Paediatrics and Child Health. *Withholding and Withdrawing Life Saving Treatment in Children: a Framework for Practice.* 1997 RCPCH, London.

question of the doctors prioritising usage of that resource. A18

It is unclear when doctors can disregard national guidelines or what sanctions might be applied.[32] Doyal and Wilsher advocate using guidelines to exclude the current use of inappropriate and legally unsafe arguments to justify withholding treatment although they favour the maintenance of clinical discretion.[33] Several consultants reserved the right to ignore guidelines:

I don't involve patients in resuscitation status, unless they are young patients that I would not resuscitate, because it's an unfair burden (on the patient)...there are guidelines on this so I ignore them since I don't agree with them. A2

There are so many exceptions...if you have rigid, inflexible guidelines...you'd breach them all the time...having guidelines oversimplifies the theory - it doesn't allow you to follow your own beliefs. D4

If they say you can't dialyse people over 70 I'll still do it. A10

What appears to be state-of-the art this year is not so next year...there needs to be recommendations with a possibility of case by case consideration. C1

Guidelines enable decision-makers to believe decisions have been made the 'right' way.[34] A danger exists with any form of guidance in that it can become dated, or can prevent scientific development.[35] They may lead to deteriorating standards of care.[36] Even those who supported them were concerned about their role as evidence in malpractice actions:

I'm writing some national guidelines at the moment...The government's guidance is that if you don't adhere to them...you can be sued. A32

There should be national guidelines that back decisions not to treat certain conditions...at the moment we are under pressure to treat everything which is the only safe thing to do medico-legally. C9

Consequently, doctors call for guidelines to allow 'discretionary judgment'[37] but if too much discretion is allowable, guidelines are worthless.

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[32]See: Payne K et al. Physicians' Attitudes about the Care of Patients in the Persistent Vegetative State: A National Survey. *Ann.Intern.Med.* 1996;**125:**104-110, in particular, p109 and Murphy DJ, Finucane TE. New Do-Not-Resuscitate Policies. *Arch.Intern.Med.*1993;**153:**1641-8, at p1643.

[33]Doyal L, Wilsher D. Towards guidelines for withholding and withdrawal of life prolonging treatment in neonatal medicine. *Archives of Disease in Childhood* 1994;**70**:F66-F70 at F76 and F68. Like them, this thesis has found evidence of poor quality ethical reasoning by some consultants.

[34]Ibid, at pF69.

[35]One of the consultants (a professor with over 35 years experience) related how, because of the parents' religious views, he kept a comatose child with Reyes Syndrome on life support for much longer than normal. The child began to come out of her coma and is now fully recovered. Evidence based, cost-effective healthcare guidelines would probably have prevented him acceding to the parents' wishes and would have cost the child her life. See also, Harpwood V. Guidelines in medical practice: the legal issues. *Cephalagia* 1998; Supp 21:56-62 at p61.

[36]See, for example, *Wickline v State* 228 Cal. Rptr at 661. See also, Miller FH. Denial of Health Care and Informed Consent in English and American Law. *American J.Law and Medicine* 1992;**18,**1-2:37-71 at pp49-50.

[37]Strong C. Defective infants and their impact on families: ethical and legal considerations. *Law, Medicine and Health Care* 1983; **11,**4:168-181 at p171.

7.1.2.2 Improving the decision-making process

Some guidelines advocate that end-of-life issues should be discussed with patients[38] but many doctors invoke therapeutic privilege to avoid this.[39] This could be to cover their difficulties in communicating such information sensitively or feeling a sense of failure. Conflicts may arise because 'the physician's goal of treatment may have changed whereas the patient's did not'.[40] Veatch proposes patient-physician 'buddying' with a focus on 'deep-value pairing'.[41] Savalescu, in reply, suggests an attractive solution of doctors holding rational discussions with patients.[42] However, this presupposes that there is no power imbalance between the parties and lacks a solution for when competent patients act 'bizarrely'[43] or refuse to enter negotiations.[44] The current NHS system fails to facilitate spending time discussing patient values and treatment options resulting in a form of physician abandonment. Increased consultation time and greater understanding of decision-making theory could improve matters.[45] Improving doctors' communication skills is another way to improve decision-making since communication problems were perceived as the largest barrier to high-quality decisions:

> *Misunderstandings, communication problems: you try and communicate well but we don't always succeed.* D4

> *Some of the problems arise when we haven't actually devoted enough time to discussions and talking to other people.* B8

> *We should learn to talk more clearly...(but)...there are some people who do not understand and do not want to understand.* A27

A few consultants identified improved training as necessary:

> *Improvement of training (clinicians, psychiatrists, managers)...continuing the progressive improvement in attitudes of one to another...Those factors would improve the decision-making process but...decisions should be made between the clinicians and the patients, not by some centralised body.* A4

> *We would benefit from more case conferences.* A11

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[38]For instance, the guidelines relating to resuscitation issued by British Medical Association and Royal College of Nursing. RCN & BMA *Joint Statement on Cardiopulmonary Resuscitation* March 1993 BMA, London, updated May 1999: *Decisions relating to cardiopulmonary resuscitation: A statement from the BMA and RCN in association with the Resuscitation Council (UK).* May 1999, http://web.bma.org.uk/public/ethics.nsf BMA, London.

[39]See: Doyal L, Wilsher D. Withholding cardiopulmonary resuscitation: proposals for formal guidelines. *BMJ* 1993;**306:**1593-6, at p1594: Padkin A, Robinson R. Letter: DNR policy *J. Roy.Coll.Physic.* 1993; **27,**3:335 and Williams R. The 'do not resuscitate' decision: guidelines for policy in the adult. *J.Roy.Coll.Physic.* 1993;**27,**2:139-140.

[40]Headley J. The DNR Decision - Part II. Ethical Principles and Application. *Dimensions in Oncology Nursing* 1991;**5,**2:34-7 at p36.

[41]Veatch R. Abandoning Informed Consent. *Hastings Center Report* 1995;**25:**5-12. See also: Veatch RM. Modern Vs. Contemporary Medicine: The Patient:Provider Relation in the Twenty-First Century. *Kennedy Institute of Ethics J.* 1996;**4:**366-370, in particular, p369.

[42]Savalescu J. Rationalism and Medical Decision-Making. *Bioethics* 1997;**11,**2:115-129.

[43]As, for instance, in the case of *R v St George's Healthcare NHS Trust ex p S* [1998] 2 FLR 728.

[44]See: Savalescu J, Momeyer R. Should informed consent be based on rational beliefs. *J. Medical Ethics* 1997;**23:**282-8.

[45]See Eraker SA, Politser P. 'How decisions are reached: physician and patient'. In Dowie & Elstein, op cit n12 at pp379-434. Also, Goldstein WM, Hogarth RM (Eds) *Research on judgment and decision making.* 1997 Cambridge Series on Judgment and Decision Making Cambridge University Press, Cambridge.

Improved data may improve decision-making though its presentation and interpretation creates difficulties.[46] The phenomenon of physician biases affecting this process has been recognised.[47] The General Medical Council considers doctors have a responsibility to 'self-audit' patient care even thought self-auditing is flawed.[48] There were contrasting opinions regarding the value of improved clinical data and clinical audit as the basis for improving decision-making:

> *Keeping up to date with evidence of trials so that you can have an ever more accurate prediction of an individual's outcome based on current research using the current methods of treatment.* A7

> *Medicine isn't an exact science...a lot of it is just feeling and intuition...there will always be the patient who survives against the odds.* B3

> *Data would be useful to see if our decision-making is correct but I'm not sure we should use the data to make decisions.* A31

Although the U.S.A. has statutory exceptions to treatment,[49] similar to those in the guidelines issued by the Royal College of Paediatrics and Child Health,[50] none of the consultants proposed a statutory process for medical-decision-making. Legislation tends to be inflexible.[51] Currently, only controversial issues are subject to government controls.[52] Legislation can lead to costly challenges, alleging inappropriate withholding or withdrawing of treatment, and over-treatment hence doctors prefer non-mandatory, non-governmental guidelines.[53] The advantage of legislative examination of medical decision-making is that the views of others beside doctors can be sought whereas medical guidelines frequently lack input from 'outsiders'.[54]

7.1.2.3 Who should be involved?

Only three of the eighty-five consultants identified greater patient involvement as a way to improve decision-making:

> *By giving them more information...more responsibility...on the patient, not necessarily to make the decision but to have a more informed element on what I'm advising.* C5

> *We should be making those decisions before (implementing treatment)...you should be saying to the patients, if we do this and it goes badly wrong, these are the consequences - what would you want to do in that situation?* A17

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[46]See, for example, Andrews K. Prediction of recovery from post-traumatic vegetative state. *Lancet* 1998; **351:**1751 and Reich S et al. Clinical decision making, risk and occupational therapy. *Health and Social Care in the Community* 1998; **6,**1:47-54, in particular, p48.
[47]Christakis NA, Asch DA. Biases in how physicians choose to withdraw life support. *The Lancet* 1993;**342:**642-6.
[48]Ramsay S. Evidence against 'Bristol-case' doctors found proven. *The Lancet* 1998; **351:**1707.
[49]Rehabilitation Act 1973, s504.
[50]Royal College of Paediatrics and Child Health. *Withholding and Withdrawing Life Saving Treatment in Children: a Framework for Practice.* 1997 RCPCH, London.
[51]See: McHaffie and Fowlie in McHaffie HE; Fowlie PW. *Life, Death and Decisions: a Reflection on Neonatal Practice.* 1996 Hochland and Hochland, Cheshire at p50.
[52]For instance, see the Abortion Act 1967 and the Human Fertilisation and Embryology Act 1990.
[53]See, for example, *In the Matter of Baby K*, 16F.3d 590 (4th Cir 1994) and Commentary: Annas G. Asking the courts to set the standard of emergency care - the case of Baby K. *NEJM* 1994;**330**:1542-45.
[54]For example, the BMA issued its consultation paper at the start of the universities summer vacation with little publicity and close of consultation on 16 October 1998: BMA. *Withdrawing and Withholding Treatment: a consultation paper from the BMA 's Medical Ethics Committee* June 1998 BMA, London. See also, McHaffie and Fowlie, op cit n51 at p19.

We don't withdraw from conscious patients without their permission. What always frightens me is how much patients want to go on. A21

Team involvement was seen as useful by most consultants but some identified the difficulty of getting all to agree:

Once you start to involve other folk you get so many decisions to the contrary you can't reach a decision. D2

Things done by committee are never done. A10

Discussions with relatives are common but a possible bias as to whether involvement by non-medical professionals was welcomed was identified. Most consultants rejected involvement by non-medical professionals with the strongest objections coming from those at one hospital which possibly had less opportunity to work with non-medical professionals:

Decisions have to be based on a much more personal individual basis with the individual patient - I don't get a lot of help from (religious views). B15

I don't think lawyers, social scientists and philosophers have any idea about it. D7

Decisions should be made by the informed, professionally trained clinician and their team and by the patient...I don't want lawyers, accountants and administrators involved. D10

The decision should be clinical but with guidelines drawn up by lawyers and social scientists as medical practice must reflect the wishes of the community who in turn will have to face the unpleasant decision of how much money they are prepared to pay for the services they demand. D1

Consultants from another hospital with stronger links with the university found input from non-medical professionals useful which possibly indicated that greater interaction with other professions reduces hostility:

I brought that last decision to a meeting because I wanted people to help discuss it...In hospitals there are Ethics Committees that spend hours discussing the ethics of projects and we don't spend that time very often discussing individual cases. I think that is inappropriate. On the Ethics Committee you have a broad selection of intelligent people. A26

Having the opportunity to have a discussion forum in the unit is often quite useful with either a psychologist or someone whose area is just slightly outside...chairing the meeting. A7

Our Professor of Medical Ethics - he's a wonderful man...you present a case to him and he discusses the issues...The other person I use a lot is our hospital chaplain. A12

Procedural guidance may be issued by the courts.[55] It often aims to improve recognition of the patient's interests or views.[56] Authoritative guidelines can 'avoid the need for unwieldy applications to the courts...and...avert a situation whereby the courts encroached upon the medical profession's field of competence'.[57] Anxiety over having to justify their actions was shown.[58] Most of the consultants felt that decisions should not involve the courts:

> *Although the law can provide a measure of protection for the medical profession and in that sense can be our allies...it's not the appropriate place to sort out this sort of issue.* A15

> *The law is all black and white and medicine is all grey. I don't think the law should get involved...they should leave it to the parents and the medical profession and trust us.* A12

7.1.3 Discussion

There was an overwhelming call for more comprehensive guidance regarding resource allocation. The current system unfairly treats both doctors and patients by failing to reflect considered societal values (as opposed to media-created values). Improvements in scientific data and communication skills were perceived positively. However, guidelines and protocols threaten medical prerogative and resistance to inflexible guidance is strong because of fears over justifying non-compliance.[59] Some perceived guidelines as hindering ethical decision-making. A surprising, and sometimes vehement, distrust of the ability of other professions, and/or the public, to assist in the decision-making process in difficult or complex cases was apparent. A similar distrust of their fellows was also occasionally evident. This may be due to unfamiliarity with the type of assistance available or fear of having to logically (or legally) justify decisions based on 'clinical intuition', 'experience' or other esoteric concepts. It could be interpreted as a 'power complex'.

None of the consultants suggested encouraging increased use of advance directives to improve decision-making, possibly reflecting a desire to retain control or an underlying belief that decisions should be grounded in science not patient-preference. This suggests that either clinicians consider advance directives to be of academic interest only at present or they fear the legal implications of written documents - informal discussions seeming safer - as evidenced by the concern that guidelines should allow 'latitude'.

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[55]For instance: *Re MB* (Medical Treatment) [1997] 2 FLR 426 and *R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728 (refusal of medical treatment by competent patients). See also, Practice Note from the Official Solicitor to the Supreme Court on Vegetative State [1996] 2 FLR 375 and Practice Note from the Official Solicitor on Sterilisation [1996] 2 FLR 111.

[56]See, for instance, the advice given in *R v St Georges Healthcare NHS Trust, ex parte S* [1998] 2 FLR 728, at p759.

[57]*Auckland AHB v Attorney-General* [1993] 1 NZLR 235 at p241 per Thomas J.

[58]The doctor's actions will be judged using the *Bolam* test: *Bolam v Friern Hospital Management Committee* [1957] 1 WLR 582. The 'standard textbook' will be treated, like guidelines, as authoritative evidence of the proper practice to be adopted by the professional: *Wiszniewski v Central Manchester HA* [1998] 6 Lloyd's Med LR 223 per Thomas J at p258. See also: Hurwitz B. *Clinical Guidelines and the Law: Diligence, Discretion and Judgment.* 1998 Radcliffe Medical Press Ltd., Abingdon, and Hurwitz B. Legal and political considerations of clinical practice guidelines. *BMJ* 1999;**318**:661-4.

[59]Duff R, Campbell AGM. Moral and Ethical Dilemmas in the Special-Care Nursery. *NEJM* 1973;**289**:890-895.

7.2 Recent Proposals from the Medical Profession

7.2.1 BMA Ethics Committee: *Withholding and Withdrawing Life-prolonging Medical Treatment*

The BMA's guidance, *Withholding and Withdrawing Life-prolonging Medical Treatment,*[60] followed its consultation exercise in 1998.[61] It generated immediate public comment[62] and merits detailed examination. Numerous doctors apparently oppose it.[63] The most immediate point of concern is the evident desire of the medical profession to restore its prerogative over decision-making to the exclusion of other professionals such as medical ethicists, judges and lawyers. The role of the 'doctor in charge' (the consultant) as being responsible, and accountable, for decision-making is repeatedly emphasised.[64] This mirrors Campbell et al's argument that doctors 'must not debase their role in medical leadership...by passive acquiescence to...demands' although they acknowledge there should be 'limits to medical arrogance'.[65] There is no mention of any possible place in the decision-making process for medical ethicists who are not practising doctors. Lawyers are evidently regarded with strong suspicion hence the determination to exclude judicial scrutinising. The guidance fails to justify convincingly why the decision-making process should be so exclusive. It seems to advocate a return to the days before *R v Arthur*[66] made it clear that the courts will not allow the medical profession unfettered control over life and death. Attempts are even made to blame the judiciary for failing to extend their guidance regarding persistent vegetative state to cover other conditions where a decision to withdraw artificial nutrition or hydration may be appropriate.[67] The BMA uses this 'failure' as justification of their stance that Court review should not be needed for any of these cases. It is hard not to come to a conclusion that this document was written solely to protect doctors by excluding them from scrutiny particularly since it stresses at several points the 'anxiety' which decision-making causes doctors.[68]

7.2.1.1 The Proposed Shift in Emphasis

Probably the most contentious section is the BMA's proposed 'shift in emphasis'. It states:

> 'Debate on this subject has tended to focus on assessing the justification for withdrawing or withholding treatment. In the BMA's view the emphasis should shift to considering whether the benefits of the treatment justify the intervention. For every proposed or actual medical intervention, a judgment should be made about whether that intervention would be worthwhile, in the sense of

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[60]BMA. *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for Decision Making.* 23 June, 1999. BMA, London (updated October 2000 to take account of the Human Rights Act 1998: www.bmjpg.co.uk/withwith/ww.htm accessed 30 October 2000). Similarly, the American Medical Association has recently issued guidelines on end of life care. *JAMA* 1999;**281:**937-941.

[61]BMA. *Withdrawing and Withholding Treatment: A consultation paper from the BMA's Medical Ethics Committee.* 1998 BMA, London. Over 2000 responses to the Consultation Paper (*Withdrawing and Withholding Treatment*) were received, including from the author of this thesis.

[62]For instance, television and radio news on 23 June, 1999 contained discussion regarding its contents and more than one programme and media commentary was dedicated to it: Radio Four, *The Moral Maze* 23 June, 1999; Murray I. Doctors want final say over patients' lives. *The Times* 24 June 1999; Hawkes N. Sanctity of life tests mettle of philosophers. *The Times* 24 June 1999; Hornsnall M. 'A doctor decided she should die'. *The Times* 24 June 1999; Boseley S. Doctors to decide on right to die: BMA insists guidelines are not charter for euthanasia. *The Guardian* 24 June 1999 and Leslie A. Saturday Essay. *Daily Mail*, 26 June 1999.

[63]Keown J. Beyond Bland: A critique of the BMA guidance on withholding and withdrawing medical treatment. *Legal Studies* 2000;**20**,1:66-84. at p67.

[64]See BMA, op cit n60 at para.7, p12; para. 11.1 (a); para 13.6, p24; para. 18.2, p45 and Part 5:21, p68. See also, British Medical Association. *Consent, Rights and Choices in Health Care for Children and Young People*. 2001, BMA, London at p118.

[65]Campbell AGM, et al. Treatment Dilemmas in Neonatal Care: Who Should Survive and Who Should Decide? *Annals New York Academy of Science* 1988;**530:**92-103 at p97.

[66]*R v Arthur* (1981) *The Times*, 6 November 1981.

[67]BMA op cit n60, Foreward at p ix.

[68]Ibid, at pxviii and p57.

providing some benefit to the individual patient.'[69]

Hidden in these innocuous words is a huge change to the whole way in which medical treatment has been provided for centuries. The presumption has always been in favour of giving treatment and hence, reasons not to give treatment or to withdraw treatment have been looked for when the patient's condition or prognosis is very poor. The BMA now proposes that there should, *de facto*, be a presumption **against** giving treatment to any patient. Doctors should seek positive reasons why a patient should receive medical treatment.[70] This point is revisited later: 'decisions to provide treatment, including artificial nutrition and hydration, need to be justified'.[71] This change must be challenged at the earliest opportunity. Not least, this is because, later in the same paragraph, the BMA makes it clear - despite its cursory recognition that 'each patient has his or her own values, beliefs, wishes and philosophies' - that 'benefit' is to be construed solely as 'net health benefit'.[72]

7.2.1.2 The Primary Goal of Medicine

The BMA holds that the primary goal of medicine is to provide physiological (health) benefit.[73] Therefore, they suggest, a duty to provide treatment no longer exists if this is not possible. However, it cannot be for the medical profession to dictate the boundaries of their legal duty of care. The BMA focuses on the 'level of recovery that could reasonably be expected'.[74] Where the decision to withhold or withdraw treatment is premised upon a determination of 'futility' or 'survival prospects' patients need some protection so that there is consistency in interpretation of these conditions. The BMA continually emphasises the construing of 'benefit' as 'health benefit' because it suggests this will introduce 'greater clarity about the legitimate scope and process of decision making by health professionals'. This, the guidance says, will 'challenge' the apparent difference felt by many concerning withholding as opposed to withdrawing treatment.[75] The BMA fails to explain why, as stated in its consultation document, it 'can see no ethical difference'[76] although 'some...intuitively feel there is an important distinction'.[77] The evidence obtained in this thesis suggests that most consultants recognise a difference and distinguish between withholding and withdrawing treatment in their answers although the questions had been designed not to differentiate. The difference is not just about distinguishing acts from omissions nor is it just emotional. The difference goes deeper because benefit is not to be construed solely as 'health benefit'.[78] Consequently, the interviewee consultants considered different factors when deciding whether to withhold or withdraw treatment. However, the BMA suggests that once decision-making is firmly back under the control of the medical profession the 'doubts' that non-medical professionals have raised, in its opinion inappropriately, will be removed. Pretending such differences do not exist, or should not exist, does little service to those who are actually making such decisions regularly. This over-emphasis on a scientific model of decision-making will only increase the anxiety it seeks to avert since the subconscious message given is that doctors who take into account other factors are failing to meet the

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[69]Ibid, at pp1-2.
[70]Since 'life-prolonging' treatment can include almost any medical intervention from antibiotics to vaccinations the change in emphasis places everyone at risk if they fail to meet some medical 'norm'.
[71]BMA op cit n60, para. 13.3 at p23.
[72]Ibid, para. 1.1 at p2.
[73]Ibid, para. 1.1 at p1.
[74]Ibid, para 2.1 at p5.
[75]Ibid, para. 6.1 at p11.
[76]BMA. *Withdrawing and Withholding Treatment* op cit n61 at para 2.9.1.
[77]Ibid, para 1.1 at p1.
[78]For discussion on this point in relation to BMA consultation paper see: The Linacre Centre for Health Care Ethics. Withdrawing and Withholding Treatment: A Response to "Withdrawing and Withholding Treatment: A consultation paper from the BMA's Medical Ethics Committee" 1998 The Linacre Centre, London. Available on www.linacre.org/wwt.html accessed October 1998.

standards of their profession.

By contrast, later in the guidance, the BMA, surprisingly, accepts that it may be appropriate to provide even 'futile' care in the short-term to enable a competent patient 'achieve a particular goal or sort out their affairs'.[79] This is particularly significant since it emphasises the 'individual' nature of the decision. The guidance also suggests that there are two strands to this decision: what is appropriate for the individual patient and what is appropriate once the needs of the rest of society and the limited nature of societal resources have been taken into account.[80] Unfortunately, it introduces another, highly variable, condition: whether the 'doctor in charge' considers that the patient will be able to achieve the stated goal.[81] This reintroduces a scientific evaluation when it has already been determinative as to whether the patient is a suitable candidate for treatment. Scientific data do not recognise the effects of hope and love on people's abilities to meet goals. Only cursory recognition is given to the fact that the patient who is refused the opportunity to achieve a life goal may require 'ongoing support' to help them accept this.[82] The 'abandoned' patient is referred to a colleague for palliative care or back to his/her GP.[83] The guidance fails to address the issue that inadequate resources means that good quality palliative care and/or counselling is not available to all. Doctors 'see their dying patients only when nursing staff call them to adjust drug treatment'.[84]

7.2.1.3 The Exclusion of the Courts

The BMA 'does not believe' decisions regarding the withholding or withdrawing of treatment from patients with Alzheimer's disease or severe stroke should be scrutinised by the courts.[85] By analogy with such cases, it suggests that PVS cases should also not require judicial approval.[86] The BMA challenges the authority of the courts regarding the declaratory process currently employed.[87] Only in 'rare cases' should legal review be necessary.[88] By excluding the courts, the medical profession can dispense with the existing guidance they have laid down and, unchecked, alter the 'rules'. The BMA seems to do this by suggesting that a diagnosis of PVS can be confirmed at six months[89] contrary to the opinion of experts such as Keith Andrews and existing judicial guidance which requires twelve months to succeed traumatic injury before the diagnosis is fixed.[90]

Virtually the only time the BMA accepts that the courts might have a legitimate role to play is regarding pregnant women and the refusal of Caesarian sections.[91] Presumably this is because the courts, to date, have always supported the medical profession and found ways to enable treatment to proceed. If doctors believe a woman has been 'overwhelmed'[92] by the suddenness of the decision but the court finds her competent to refuse

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[79]BMA, op cit n60, para. 11.1(a) at p18.
[80]Ibid.
[81]Ibid.
[82]Ibid, at p19. Also, para. 26.1 at p64, the BMA suggests families may need to be offered counselling.
[83]Asai A et al. Medical decisions concerning the end of life: a discussion with Japanese physicians. *J.Med.Ethics* 1997;**23**:323-7.
[84]Mirando S. Doctors can benefit from spending time with their dying patients. *BMJ* 1999;**318:**1763-4 at p1763.
[85]BMA, op cit n60, para. 3.4 at p8.
[86]Ibid, para.21.1 at p54.
[87]Ibid, para 21.1 at p55.
[88]Ibid, para 18.4 at p49.
[89]Ibid, para 21.1 at p54.
[90]See: The Permanent Vegetative State: Review by a Working Group Convened by the Royal College of Physicians and Endorsed by the Conference of Medical Colleges and their Faculties of the United Kingdom. *J.Roy.Coll.Physic.* 1996;**30:**119 and Practice Note from the Official Solicitor to the Supreme Court on Vegetative State [1996] 2 FLR 375.
[91]BMA, op cit n60, para. 13.7 at p24.
[92]As in *Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097.

a Caesarian section,[93] the BMA may then seek to place these decisions within their proposed umbrella of decision-making. After all, *Re F* holds it is for doctors to decide who is competent.[94] The adverse effect this would have upon the future of patient autonomy is frightening.

7.2.1.4 Patient Merits/Quality of Life

The guidance states that 'the doctor's role is not to assess the value or worth of the *patient* but that of the *treatment*'.[95] Yet this is exactly what doctors do, often unconsciously, as shown in the empirical evidence for this thesis.[96] Keown argues that the guidance indicates a preference for quality of life considerations that endorses judgments about the worth of the patient.[97] The BMA rejects the concept that life alone is a sufficient justification for its prolongation, particularly given that patients compete for resources. The BMA does suggest that treatment 'may be of benefit' if an individual is 'able to interact with others' and/or is 'aware of his or her own existence and having an ability to take pleasure in the fact of that existence' and/or has the 'ability to achieve some purposeful or self-directed action or to achieve some goal of importance to him or herself'.[98] The preceding consultation document likewise stated that 'life (is) a value to be preserved only insofar as it contains some potentiality for human relationships'.[99] Yet doctors withdraw life-saving treatment even though the relationship potentiality has been realised but the physical potentiality of growing into a healthy child/adult has not. Not all such decisions are based on 'pain' or 'intolerability'.[100] David Glass seemed 'able to interact', albeit in a limited manner, yet his doctors considered it 'in his best interests' for him to die and the courts refused to support his mother's action.[101] Had this guidance been published earlier, would the court have interpreted it in his favour? Possibly it might, but if the BMA has its way and excludes independent scrutinising of such decisions, the answer will not be known. This case is particularly concerning since it seems that the doctors were instructed by the hospital's Chief Executive to give the child diamorphine.[102] This raises the spectre of hospital managers, possibly with no medical training, suggesting that the time has come to withdraw treatment or hasten death with the use of pain-killers as a way to combat bed shortages. Unless the doctor is prepared to defend the patient's quality of life to his/her peers, it will be very difficult to oppose.[103] Certainly, the BMA seems anxious to ensure that cases like his and those of people with 'advanced dementia or very severe stroke' are controlled exclusively by the medical profession. The BMA states it 'does not believe these cases should routinely be subject to Court review'.[104] It fails to mention that the GMC, and the media,

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[93]As in *R v St George's Healthcare NHS Trust, ex parte S.* [1998] 2 FLR 728.
[94]*Re F (mental patient: sterilisation)* [1990] 2 AC 1.
[95]BMA, op cit n60, para. 1.2 at p3.
[96]Doctors have the power to enable patients to 'leapfrog' waiting lists for patients they believe should take priority. More conscious ways of taking account of patient 'merit' have also been proposed: Leonard S. Penalty points scheme rations heart surgery. *The Sunday Times* 18 July 1999.
[97]Keown J. Beyond Bland: A critique of the BMA guidance on withholding and withdrawing medical treatment. *Legal Studies* 2000;**20**,1:66-84, at pp72-74.
[98]BMA, op cit n60, para. 1.2 at p4.
[99]BMA, op cit n61 at para 2.9.7.
[100]See *Re C (Medical Treatment)* [1998] 1 FLR 384 (the child with spinal muscular atrophy).
[101]Horsnell M. Relatives stormed a ward to resuscitate this boy. Doctors say he should be allowed to die. *The Times* 22 April 1999. Dyer C. Mother loses court battle on right to life. *The Guardian* 23 April 1999. Mrs Glass was one of the participants in the debate regarding the BMA guidance on the *Moral Maze*, op cit n62.
[102]Jones T. Mother fails to win 'right to life' ruling. *The Times* 23 April 1999. The Court of Appeal also ruled against her:*Rv Portsmouth NHS Trust, ex parte Glass* [1999] 2 FLR 905. See also: Dyer C. Mother loses fight over son's treatment. *The Guardian* 22 July 1999 and Gibb F. Doctors who wanted to let child die did not act illegally. *The Times* 22 July 1999.
[103]The only protective measure suggested when competition for resources means that hospital managers begin to suggest that some patients have 'bed-blocked' long enough is that of the 'second medical opinion': BMA, op cit n60, para. 8.1 at p13; para. 17.2 at pp38-9 and para. 22.1(a) at pp57-8.
[104]Ibid, para. 3.4 at p8 and para. 21.1 at p54.

have criticised some doctors for withdrawing or withholding artificial nutrition from such patients.[105] Even Williams is concerned at the concept that autonomous patients, who believe their life would continue to be worthwhile, could have treatment withheld because a third party judges their future quality of life unacceptable.[106] The guidance increases anxiety by warning doctors that they could be the first to be challenged.[107]

There is a presumption against treating babies and young children: '(treatment) should only proceed where it would provide a net benefit to the patient'.[108] This rests firmly on a quality of life determination despite the avowed rejection of this approach.[109] 'Standard policies and guidance' have limited effectiveness and the profession does not have a good record at policing itself.[110] Stating that treatment should not be withheld simply because it might be easier to do this than withdrawing treatment later does not reflect the reality of some doctors' current practice.[111] Several consider their role is to ensure patients do not survive because they may become vegetative.[112] Since this is current practice, as the BMA recognises, though it does not approve, how will excluding their decisions from the scrutiny of other professionals help ensure that difficult decisions are appropriately made and that some patients are not needlessly sacrificed?

7.2.1.5 Patient Autonomy

Patient autonomy is given support and it is reassuring to see that the BMA states that patients should not be pressured into accepting treatment.[113] Yet, as discussed earlier in this thesis, there is evidence that duress occurs particularly regarding Caesarian sections. Some consider it appropriate to 'educate' patients whose 'irrational or bizarre' views prevent them accepting that 'doctor knows best'.[114] The guidance is silent regarding the fact that doctors will present clinical information in such a way that it is more likely the patient will not request active treatment.[115] It is also worth noting that patients refusing treatment are still not worthy of 'full' information about their condition.[116] Yet patients who receive full information may then accept medical advice.[117] However, parents apparently merit 'full, clear and accurate information' yet no justification for this difference is given.[118] This could be a potential source of future challenge by patients like Mrs Sidaway.[119] According to the guidance, parents are also entitled, unlike other patients, to information regarding the doctor's own success rates regarding the particular treatment or procedure. This is obviously in response

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[105]Horsnell M. GP Guilty of letting elderly patient starve. *The Times* 26 March 1999; Wilson E. GP in mercy killing case escapes being struck off. *Daily Mail* 27 March 1999.
[106]Williams A. Health professionals have an ethical duty... *J.Med.Ethics* 2000;**26:**85-88 at p86.
[107]BMA, op cit n60, para. 21.4 at p56.
[108]Ibid.
[109]Ibid, para. 1.2 at pp2-3. The research for this thesis found that Quality of Life seemed more important to doctors when the patient concerned was a child. See also: Rogers L. Having disabled babies will be 'sin', says scientist. *The Sunday Times* 4 July 1999.
[110]See, for instance, the failure to 'police' the heart surgeons effectively at Bristol Royal Infirmary with the result that excessive numbers of babies died. Horton R. Commentary: How should doctors respond to the GMC's judgments on Bristol? *The Lancet* 1998;**351:**1900-1901. Ramsey S. Evidence against 'Bristol case' doctors found proven. *The Lancet* 1998;**351:**1707.
[111]BMA, op cit n60, para. 6.2 at pp11-12.
[112]It is worth noting that the babies who die as a result of poor obstetric care cost the NHS much less in compensation than those that survive with major disability.
[113]BMA, op cit n60, para. 9.1 at pp13-14.
[114]Savalescu J, Momeyer RW. Should informed consent be based on rational beliefs? *J.Med.Ethics* 1997;**23:**282-8.
[115]See discussion earlier in this thesis.
[116]BMA, op cit n60, para. 9.3 at p14.
[117]See earlier discussion in this thesis and McCafferty C. Won't consent? Can't consent! Refusal of Medical Treatment. *Family Law* 1999;**29:**335-336.
[118]BMA, op cit n60, Part 3B at p27.
[119]*Sidaway v Board of Governors of the Bethlem Royal Hospital and Maudsley Hospital* [1985] AC 871.

to the severe criticism of the doctors involved in the 'Bristol babies' case.[120] The advice given regarding Advance Directives/Statements seems to accord with accepted ethical and legal opinion. The need to respect patient confidentiality is recognised yet, strangely, the BMA considers it appropriate to seek information from relatives about the patients 'wishes and values', even though the patient has specifically stated that his/her condition is not to be discussed with them.[121] This could contravene patient confidentiality rules as well as form a future area of challenge under the Human Rights Act (HRA) 1998. The updated guidance also recognises a slight possibility that the HRA 1998 could lead to foetal rights such as a right to life, or a right not to be discriminated against, overriding maternal autonomy.[122]

7.2.1.6 Incompetent Patients

Emphasis is made regarding the optimising of conditions for assessment when seeking to discover the awareness state of any patient.[123] The guidance says doctors should decide '(what) would be considered acceptable to the individual patient if he or she were able to express a view'.[124] This adoption of a substituted judgment approach is typical of the muddled reasoning demonstrated by many of the consultants interviewed for this thesis. The BMA recognises that many doctors employ the model of 'ethical' reasoning which questions whether they 'would wish to have treatment themselves' in the same situation but does not question this practice.[125]

The guidance says that children and incompetent adults should be treated alike[126] so 'the ethical underpinning of paediatric, adult and geriatric medicine are the same'.[127] Yet its statement that 'there should be a presumption in favour of initiating (treatment)' whenever there is reasonable uncertainty about outcome results in different treatment.[128] This is because, as acknowledged a few lines earlier, there is an inadequate evidence base concerning treatment of children upon which to rest decisions.[129] The guidance notes that some doctors believe that parental consent is all that is needed to withhold life-sustaining treatment from babies.[130] Where the parents do not accept the doctor's advice, the BMA suggests bringing in 'additional clinical expertise' to provide 'further medical opinions' and suggests parents 'may benefit from the opportunity to speak to other parents'.[131] Nowhere in the guidance is it suggested that an ethics specialist, the hospital chaplain or religious advisors of the family might usefully be employed. This demonstrates a real hostility to the idea that these other professionals might have a useful role to play. In contrast, lawyers should be consulted when parents refuse to agree with the healthcare team's advice.[132] This seems extremely heavy-handed and is likely to exacerbate the differences of opinion which could have been avoided had the help of other professionals been

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[120]Ramsay S. Evidence against 'Bristol-case' doctors found proven. *The Lancet* 1998;**351:**1707.

[121]BMA, op cit n60, para. 18.3 at p47. This could seem to contravene patient confidentiality rules as they currently stand, as well as form a future area of challenge under the Human Rights Act 1998, Article 8(1).

[122]BMA. *Withholding and Withdrawing Life-prolonging Medical Treatment* 2nd Edn at para. 19.3 available on www.bmjpg.co.uk/withwith/ww.htm accessed 30 October 2000.

[123]BMA, op cit n60, para. 17.8 at p42.

[124]Ibid, para. 13.5 at p24. In the preceding consultation document, *Withdrawing and Withholding Treatment* op cit n61, at para.2.9.2, the BMA suggested that one way to decide what benefits a treatment holds is 'for an assessment to be made by the clinician placing themselves in the patient's position' despite the clear rejection of the 'substituted judgment' approach by our higher courts.

[125]BMA, op cit n60, para. 13.6 at p24. This reflects the findings of this thesis.

[126]Ibid, paras. 14.1 & 14.2 at p25.

[127]Ibid, at p26.

[128]Ibid.

[129]Ibid.

[130]Ibid, para. 14.2 at p25.

[131]Ibid, para. 15.2 at p30.

[132]Ibid, para. 15.2 at p30 and para.15.3 at pp30-31.

utilised. Likewise, the language employed regarding the input of 'those close to the patient' is very dogmatic: 'it is essential that those consulted are absolutely clear that, ultimately, the treatment decision is not their right or their responsibility. Rather, the decision will be made by the clinician in charge of the patient's care on the basis of what he or she considers will benefit the patient'.[133]

7.2.1.7 The Second Medical Opinion

In place of the judiciary, the BMA suggests that a Second Medical Opinion agreeing with the 'doctor in charge'[134], backed up by audit in the case of withdrawal of artificial nutrition/hydration[135], would provide sufficient protection of patient interests. This would be used where parents reject medical advice.[136] Classing this as 'independent' raises the same reservations that have been expressed regarding abortion and the use of this same restraint.[137] Reality suggests that the decision would be 'rubberstamped' since, as this thesis shows, doctors who offer a 'second medical opinion' as a way to reassure or persuade relatives to accept their views ensure that the colleague selected is likely to agree. Even where children are concerned, the BMA believes disputes between parents and doctors can mostly be resolved without recourse to the courts by utilisation of the second opinion process.[138] Yet, when they feel it is to their advantage, doctors turn to the courts.[139] In *Re M*, the doctors were not willing to simply rely upon parental consent and their own estimation of her best interests, as advocated in the guidance which had been issued a few weeks earlier, but wished to have the additional security of judicial authority.[140]

7.2.1.8 Resource Allocation

In its consultation document, the BMA excluded the issue of resources from the discussion which seemed artificial and potentially misleading[141] although later, in the same document, it acknowledged that such decisions necessitate considering the 'effect on the family, staff, the hospital and the community as well as resources'.[142] Many of the consultants interviewed suggested that the process was always affected, consciously or not, by resource availability and appropriateness of allocation. The finished guidance states that therapeutic treatments 'are not invariably given...but are weighed according to a number of factors such as...the resources available'.[143] The BMA discusses the withholding/withdrawing of treatment because of cost.[144] The influence of the market economy is evident in the acceptance that treatment decisions can be based on costs rather than science.[145] The appropriateness of doctors making economic decisions, bearing in mind their closeness to individual patients and their apparent tendency to apply poor ethical reasoning and judgmental attitudes at times, is questionable. Williams objects to the lack of ethical support given by the BMA for the

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[133]Ibid, para. 18.3 at p48.
[134]Ibid, para. 8.1 at p13; para. 17.2 at pp38-9 and para. 22.1(a) at pp57-8.
[135]Ibid, para. 22.1(c) at pp58-9. It does not state who should conduct the audit.
[136]Ibid, para. 15.2 at p30.
[137]The 'rubberstamping' of abortion requests has been blamed by the pro-life lobby for the exponential growth in the number of abortions from 23,641 in 1968 to 177,275 in 1996 in this country. Respect for Life: www.likeuk.org.
[138]BMA, op cit n60, para. 15.1 at p29.
[139]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.
[140]*Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097.
[141]BMA, op cit n61, para 2.7.
[142]Ibid, at para 2.8.
[143]BMA, op cit n60, pxvii.
[144]Ibid, para. 11.1 (d) at p20.
[145]Ibid.

'disqualification of patients who make "inequitable" demands on scarce resources'[146] but concludes 'it would be a great service to the citizenry of the U.K.' if the BMA would engage in the resource-allocation debate.[147] The BMA presumes to challenge the judiciary for holding that 'non-treatment decisions...should be based on considerations of benefit to the patient and not cost'.[148] The guidance advocates that the real costs of caring for 'irreversibly and severely brain-damaged patients' should be recognised.[149] It suggests that 'in reality, cost factors probably have a disproportionate influence on decision-making for this very vulnerable patient group'.[150] This unsupported statement raises some troubling questions. Since most referrals to court for approval of the withdrawing of life-sustaining treatment are prompted by the medical profession, is the BMA openly admitting that doctors allow cost factors to influence their attitudes towards such patients? Certainly, the empirical research findings of this thesis suggest this but where is the BMA's justification? Trying to exclude judicial scrutiny because the courts fail to consider costs whilst holding that costs are important but 'disproportionately' influential is evidence of muddled reasoning. Consequently, it is hard to believe that decision-making would be improved by allowing the medical profession unscrutinised control. Since justice in resource allocation nationally is urgently required society should decide what factors to consider.

7.2.1.9 The Decision-making process

The BMA suggests that the starting point for decision-making is clinical evidence[151] and favours the use of clinical guidelines.[152] The guidance states that doctors have an obligation to use 'the most reliable and accurate data'.[153] However, Roberton worries that the process of interpreting data introduces subjective variables.[154] Bohin fears that improving outcomes data will introduce 'a more aggressive policy for the withdrawal of care in those babies where a clear indication of severe handicap existed'.[155] Little wonder the medical profession is increasingly opposed to openness with regard to the decisions they make. To hide the decision-making process from scrutiny by ousting the jurisdiction of the courts cannot be held consistent with the rights newly justiciable in British courts under the Human Rights Act 1998. Therefore, doctors must be required not only to continue to accept independent scrutiny and arbitration they need to actively embrace open accountability. When they deny someone a life-saving opportunity of treatment, they must be clear that this decision has not been made using 'blanket' categorisations such as age or disability regardless of whether the decision has been made apparently 'consensually' with the patient concerned because, as this thesis shows, patients and families are manipulated by doctors who have been trained in gaining compliance. In particular, if a decision is made that the patient shall not receive, or shall not be offered, treatments such as resuscitation, ventilation, artificial hydration/nutrition or chemotherapy the reasons for that decision should be recorded and open for scrutiny. If there are several treatment options, this should be carried out for each option. Evidence-based medicine requires evidence. Respect for patient autonomy and patient rights requires openness. The factors considered should be identified as should the weight given to each factor along with the reason the weighting is as it is. This may seem cumbersome to a profession which has 19th century ideas about the appropriateness of

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[146]Williams A. Health professionals have an ethical duty... *J.Med.Ethics* 2000;**26:**85-88 at p86.
[147]Ibid.
[148]BMA, op cit n60, para. 18.5 at p49.
[149]Ibid.
[150]Ibid.
[151]Ibid, para. 17.1 at p38 and para. 17.10 at p43.
[152]Ibid, para. 17.2 at pp38-39.
[153]Ibid, para. 18.4 at p48.
[154]Roberton NCR: Should we look after babies less than 800g? *Arch.Dis.Child.*1993:**68**:326-329 at p328.
[155]Bohin S et al. Impact of extremely premature infants on neonatal services. *Arch.Dis.Child* 1997;**74**:F110-F113 at F112-3.

independent scrutiny but it is the only way ahead for the 21st century.

Concern regarding legal culpability is evident where it is stressed that doctors withdrawing treatment have a responsibility to ensure the patient is not adversely affected by residual drugs, particularly respiratory sedation.[156] Doctors following this advice could avoid allegations, like those made in the David Glass case, of inappropriately prescribing a respiratory depressant, diamorphine, to a patient with respiratory difficulties.[157] The guidance advocates the use of 'try-outs' of treatment where the outcome is uncertain. This advice extends to stroke patients, who should receive artificial nutrition and hydration where prognosis is unknown.[158] This could allay public concerns over 'backdoor euthanasia' but, over a year since the guidance was published, little seems to have changed.[159] The input of other healthcare professionals is mentioned but it is emphasised that the decision is the consultant's.[160] Team agreement is useful in 'cases of uncertainty'.[161] Such cases are the ones most likely to lead to conflict. Conflict management is held to be the responsibility of hospital managers and doctors seem unprepared to accept any responsibility for minimising or handling conflict ethically or professionally.[162] Although decision-making should be 'transparent and able to withstand close scrutiny'[163] a danger that decision-making could become 'routinised' is recognised.[164] It is possible to see the start of a 'slippery slope'.[165] Little advice on how to avoid this is provided apart from a non-exhaustive list of factors to consider.[166] How to balance these factors is not addressed nor is whether certain factors should have greater weight such as, for instance, the views of parents of a minor child.

7.2.1.10 Burden on Staff

Finally, the guidance notes the burden that caring for very ill patients places on staff and correctly states that employers have responsibilities regarding the well-being of employees.[167] It fails to recognise, however, the influence 'burn-out' can have on the decision-making process which was evident from the interviews for this thesis. If doctors do not recognise all potential sources of influence, their decisions are liable to be flawed, often fatally flawed, for the recipients.

7.2.2 Royal College of Paediatrics and Child Health: *Withholding or Withdrawing Life Saving Treatment in Children*[168]

The Royal College of Paediatrics and Child Health adopts the same position as the BMA that withholding and

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[156]BMA, op cit n60, para. 17.4 at p40.
[157]*R v Portsmouth NHS Trust, ex parte Glass* [1999] 2 FLR 905. See also cases like that of Dr David Moor, accused of murder: Jones T. GP 'murdered elderly patient with injection' *The Times* 14 April 1999; Wilkinson P. Honesty led to a murder charge. *The Times* 12 May 1999. Horsnell M. Thousands of doctors 'reassured by verdict' *The Times* 12 May 1999.
[158]BMA, op cit n60, para. 17.7 at p41.
[159]Dyer C. Police investigate deaths of terminally ill patients. *BMJ* 2000;**321**:981.
[160]BMA, op cit n60, para. 18.2 at p45.
[161]Ibid.
[162]Ibid, para. 18.4 at pp48-49.
[163]Ibid, para. 17.8 at p42.
[164]Ibid, para. 25.3 at p63.
[165]See discussion earlier in this thesis and also, van der Heide A et al. Medical end-of-life decisions made for neonates and infants in the Netherlands. *The Lancet* 1997; **350:**251-5 at p252.
[166]BMA, op cit n60, para. 18.1 at pp44-45. See also: Keown J. Beyond Bland: A critique of the BMA guidance on withholding and withdrawing medical treatment. *Legal Studies* 2000;**20**,1:66-84, at p77.
[167]BMA, op cit n60, para. 26.2 at p64.
[168]Royal College of Paediatrics and Child Health. *Withholding or Withdrawing Life Saving Treatment in Children: A Framework for Practice.* 1997 RCPCH, London.

withdrawing treatment are ethically equivalent but acknowledges that 'emotionally' they seem different.[169] In other respects the guidances are markedly dissimilar. Committed to serving the child's best interests, the RCPCH guidance concludes that there are five situations in which the withholding or withdrawing of treatment might be appropriate.[170] These are the brain death; vegetative state; 'no chance'; 'no purpose' and 'unbearable' situations.[171] Guiding principles are teamwork between parents and healthcare professionals, compliance with the law and respect for the rights of the child.[172] Unlike the BMA guidance, emphasis is placed on enhancing 'corporate moral responsibility'[173] through team decision-making rather than individual consultant responsibility although later it states that the consultant bears final responsibility.[174] Although euthanasia is rejected, the guidelines mandate a practice which ensures death will follow withdrawal of artificial ventilation.[175] It seems quite probable that parents are not told that continuing muscle paralysing agents in a child from whom ventilation is to be withdrawn means that death will be certain. Some parents may not realise that, in reality, survival is 'a lottery' and their child may be able to survive. Similarly, the guidance suggests that artificial hydration and nutrition should 'rarely be introduced' for a child with rapidly progressing cancer.[176] This practice has been much criticised with regard to adult patients.[177]

It is held ethical to withdraw life-sustaining treatment from a competent child who refuses it but only providing the healthcare team and the parents agree.[178] The RCPCH emphases the ethical basis of decision-making by seeking 'to define best practice'[179] rather than taking a legalistic approach like the BMA.[180] The RCPCH advocates saving lives of 'high quality' despite handicap but fails to address who should decide what is 'high quality'.[181] It is as indefinable as the RCPCH accepts 'intolerable' is.[182] The RCPCH points out that the legal touchstone is intolerability to the child,[183] yet, the five situations delineated by the RCPCH do not include this, presumably because of fears that intolerability could be based on religious objections.[184] Heart transplants are intolerable to many yet the child in *Re M* was forced to undergo one.[185] There is a lack of coherence in the RCPCH stance. Ethically it is hard to justify such an intrusion as a heart transplant on an unwilling patient. The legalist stance is adopted by doctors when it suits them and children's views carry little weight. In Child B the court accepted the clinical view that further treatment would be too burdensome despite evidence she could and would tolerate it.[186] Consequently, only cursory recognition is made of the concept that the views of a child-patient can 'help adults make more informed decisions'.[187] Doctors are advised to continue treatment when they think fit despite 'presumption of competence'.[188]

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[169]Ibid, para 2.1 at p9.
[170]Ibid, para 3.1.3 at pp19-20.
[171]Ibid, Summary at p7.
[172]Ibid, para. 2.3.1 at p10.
[173]Ibid, para 3.1.1 at p19.
[174]Ibid, para. 3.3.1 at p22.
[175]Ibid, para 2.4.3 at p14.
[176]Ibid, para 3.1.4 at p20.
[177]Horsnell M. Police check hospitals over 'backdoor euthanasia'. *The Times* 6 January 1999.
[178]RCPCH, op cit n168, para. 2.3.2.8 at p12.
[179]Ibid, para 2.4 at p13.
[180]See: Keown J. Beyond Bland: A critique of the BMA guidance on withholding and withdrawing medical treatment. *Legal Studies* 2000;**20**,1:66-84, at pp81-82.
[181]RCPCH, op cit n168, para. 2.7.1 at p17.
[182]Ibid, para 2.7.3 at p18.
[183]Ibid, para. 2.4 at p13.
[184]For instance, the rejection of blood transfusions by many Jehovah's Witnesses.
[185]*Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097.
[186]*R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055.
[187]RCPCH, op cit n168, para 2.4.1 at p14.
[188]Ibid, para 2.6.1 at p16.

Selectivity in asking colleagues to give second opinions to resolve conflict should be 'recognised and guarded against' if the dissent is with colleagues.[189] Presumably the RCPCH considers selectivity is acceptable if dissent is with parents since there is silence on this point. Several consultant interviewees for this thesis admitted such selectivity. Ethics committees are rejected as 'too remote' because they dissociate the decision-making process from the medical team[190] although the RCPCH admits others consider them 'patient-centred' and reflective of informed societal views.[191] If introduced, the RCPCH believes ethics committees should be independent of NHS Trusts to prevent financial considerations influencing decisions[192] although it recognises that doctors themselves consider resource implications.[193] The most concrete proposals are for improved training and research into children's competence and what levels of disability are 'tolerable'.[194] It perpetuates the status quo and gives little guidance regarding the sorts of cases where dispute over 'best interests' or competence ends in the courts.

7.3 Recent Government Proposals

7.3.1 Reforming the resource allocation process

Since the interviews for this thesis were carried out in 1997, changes to the way the NHS allocates resources have been implemented or proposed. Will these address the difficulties identified at that time? In 1999, the market economy in health was abolished (in theory).[195] Greater lay input via Primary Care Commissions is designed to facilitate greater recognition of local needs. However, as recognised with the Oregon Plan, some central control needs to be in place hence health targets, treatments and guidelines will be issued via the Department of Health, NICE and CHI. There will still be regional inequalities but blame can be deflected from government to the public. Identifying what treatments are appropriate for different conditions and which the NHS should fund is a long overdue measure. However, NICE lacks the resources to conduct a fully comprehensive review. It is becoming clear that the choice of treatments it considers is politically driven not scientifically driven.[196]

The government has promised more money, more staff and improved facilities for the NHS.[197] This will address some concerns.[198] However, it was clear from the consultants' comments that funding is not always the issue, how it is used is. Some devolution of power from central government to local health services is planned but health will not be taken out of the political arena. Oakley condemns the 'arid and artificial division between medical and social models of health' which suggest that the social factors causing babies (and

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[189]Ibid, paras 3.4.1 and 3.4.2 at p23.
[190]Ibid, para 3.4.4 at p23.
[191]See, for instance, Freeman MDA. 'Sterilising the Mentally Handicapped'. In Freeman MDA (Ed) *Medicine, Ethics and the Law*. 1988 Stevens & Sons, London at p70.
[192]RCPCH op cit, n168, para 3.4.4 at p24.
[193]Ibid, para 5.2 at p26.
[194]Ibid, paras 5.1.and 5.3 at p26.
[195]Health Act 1999.
[196]For example, the alteration of stance regarding Relenza: NICE. *NICE issues guidance on zanamivir (Relenza) for influenza*. 21 November 2000, www.nice.org.uk. Accessed 5 December 2000. Also, the announcement that the provision of infertility treatment will be reviewed because of regional inequalities: NICE. Response to announcement regarding Infertility Guidance. November 2000, www.nice.org.uk. Accessed 5 December 2000.
[197]Department of Health. *The NHS Plan: A plan for investment, a plan for reform*. (Cm 4818-1) The Stationery Office, London. Available on www.nhs.uk/nhsplan accessed 7 August 2000.
[198]Dobson R. NHS still rattling tins for funds. *BMJ* 2000;**321**:982. This discusses the forthcoming report from Charities Aid Foundation, Philanthropic Funds in London's Health Care (December 2000) www.cafonline.org.

presumably, older patients) to die can be considered as beyond government remit or too expensive to address and so investment in medical technology is easier.[199] The increased funding of the NHS will fail to produce equity of outcome if investment fails to address social factors as well. The pooling of resources between health and social services is returning to a model similar to that which existed in the 1970's but will do little to investigate or address social influences on health. The pooling of resources is merely designed to prevent patients 'falling in the cracks between the two services'.[200] The NHS Plan promises that by 2004 'widespread bedblocking' will have ended.[201] However, unless there is sufficient funding, sufficient support for people in their homes or sufficient acceptable quality residential places, beds will still be occupied inappropriately and treatment will be withheld from other patients.

Waiting times are currently denying many patients appropriate and timely treatment. They are used 'to balance supply and demand'.[202] The NHS Plan places emphasis upon early diagnosis through initiatives to ensure speedy access to GPs or alternative sources of advice such as NHS Direct, pharmacies and clinics.[203] However, access to consultants or 'specialist GPs' will still be via the GP 'gatekeeper'.[204] By 2005, the wait for inpatient treatment will be cut from eighteen months to six.[205] The problem will still remain as to how to ensure that patients are not treated, at the expense of non-treatment for others who would benefit more, simply because they have reached the maximum waiting time. The politics of healthcare means that the scientific model of treating the most treatable and the medical model of treating the neediest are displaced in favour of reducing waiting lists.

Measures to address inequality in health and access to services are planned.[206] The difference between equity in outcome and equity in access is not recognised.[207] This means that a tension between the two will continue with the result that treatment could be withheld from some patients thereby resulting in lower quality of life simply because others will gain access before them. One important improvement, which will improve the ability of patients to make autonomous choices, is the introduction of a free, nationally available translation and interpretation service by 2003.[208] The slow introduction of this service is regrettable. It is unclear whether it will be available to children to access privately so they do not have to rely upon their parents or carers to act as an intermediary between the doctor and themselves. Advocates of children's rights to make autonomous choices and to be involved in their medical care will be keen to see it made freely available.

Improving outcomes[209] and tackling regional inequality in the availability of newly licensed drugs for cancer patients are major targets.[210] However, there seems to be greater emphasis upon female cancers at the expense of tackling inequality with regard to research, diagnosis and treatment for male cancers.[211] The emphasis upon doubling the number of adult cancer patients entering drug trials is concerning.[212] Whilst this will make the

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[199]Oakley A. *Essays on Women, Medicine and Health.* 1993 Edinburgh University Press, Edinburgh at p122.
[200]Department of Health, op cit n195, Summary.
[201]Ibid, Chapter 12, para 12.9.
[202]Ibid, Chapter 12, para 12.14.
[203]Ibid, Chapter 12 paras 12.1-12.7.
[204]Ibid, Chapter 12, para 12.7.
[205]Ibid, Chapter 12, para 12.20.
[206]Ibid, Chapter 13.
[207]Ibid, Chapter 13, para 1.313.
[208]Ibid, Chapter 13, para 13.14.
[209]Ibid, Chapter 14, para 14.3.
[210]Ibid, Chapter 14 para 14.11.
[211]Ibid, Chapter 14, paras 14.5 and 14.6.
[212]Ibid, Chapter 14, para 14.7.

new (third) generation oncology drugs available to more people than is currently the case, it means that many patients will continue to receive the less effective (first generation) drugs because they are in the control group. Patients will not know which drug they are receiving. This is exploiting the vulnerable who may feel pressurised into being 'guinea pigs'. Several consultants expressed concern over gambling with patients' lives. This 'solution' will exacerbate the problem. Instead, funding should be directed towards making freely available the many, already proven, second-generation oncology drugs that are currently black-listed.

With regard to heart disease, waiting times will be reduced which will address some of the problems. However, some measures need to be treated cautiously. Training ambulance personnel to deliver thrombolytic drugs to 'heart attack' patients[213] could lead to inappropriate, and potentially fatal, treatment being given. If the patient is suffering from a cerebro-vascular attack, such drugs exacerbate the bleed. Cynically, the 'trade-off' of improved recovery for some against early death for others might be politically acceptable as a way to reduce NHS costs as long as the public does not realise.

Failings in mental health service provision will be tackled with more staff. Early intervention for young people with mental illness will be improved but compliance with treatment is likely to be poor if it will continue to be delivered through the presently adult-centred system. Mentally ill offenders will receive better access to treatment[214] but there is no mention of improving access to treatment for those with learning disabilities who also have mental health problems. There is no mention at all about improving the availability of the new generation psychiatric drugs. This means that many patients will continue to suffer unpleasant side-effects which impinge upon their willingness to comply with treatment. The financial costs involved for society mean that its most vulnerable members will continue to carry physical, social and emotional costs for the benefit of others. There is more emphasis on control than cure and very little caring.

Whilst the NHS Plan seemed to place 'service-user preferences' at the heart of its consultation process, only the elderly receive clear identification of their needs and wishes.[215] Ageism will not be tolerated particularly in regard to non-resuscitation.[216] However, there is scope for ageist non-treatment protocols to be developed as long as age is not the sole criterion.[217] There is no mention of the new Alzheimer's drugs so it seems likely that provision of these will continue to be sporadic and unequal. Much of the Plan focuses upon keeping patients out of hospital through greater support in the community[218] rather than enhancing access to treatment for the disabling conditions of old age such as cataracts and hip degeneration. Consequently, the Plan itself seems 'ageist'.

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[213]Ibid, Chapter 14, para 14.21.
[214]Ibid, Chapter 14, para 14.36.
[215]Ibid, Chapter 15, para 15.3.
[216]Ibid, Chapter 15, para 15.6.
[217]Ibid.
[218]Ibid, Chapter 15, passim.

7.3.2 Reforming the Individual Patient Decision-making Process

Based on earlier proposals from the Law Commission[219] and the House of Lords,[220] *Who Decides?*[221] set out to gauge whether legal, medical and lay opinion remained the same.[222] Acknowledgment was made in *Who Decides?* of increased healthcare expenditure due to demographic and technological changes.[223] In October 1999, *Making Decisions* was published.[224] It fails to address several significant concerns raised in *Who Decides?* The legislation proposed in *Making Decisions* is subject to the availability of parliamentary time.[225] There now seems little enthusiasm to legislate rapidly, although similar legislation, the Adults with Incapacity (Scotland) Act 2000, will soon be in force.[226] The proposals say that children over sixteen years should be treated as adults.[227] Legislation regarding independent supervision of medical and research procedures or public law protection for people at risk will not be forthcoming.[228] Legalising euthanasia is expressly rejected.[229] The key principles when deciding for a person without capacity are, according to the government, capacity, best interests and a general authority to act reasonably.[230] The reform proposals extend to creating new powers of attorney for healthcare decisions; new powers for the courts, a new Court of Protection and ways to recover expenditure made on behalf of the incompetent person. The strong presumption in favour of saving healthy lives, albeit without using force, that was evident in *Who Decides*? has gone.[231] *Making Decisions* concentrates on those who probably will not recover capacity and could be seen as an unwelcome burden both on their families and the state.

7.3.2.1 Measures to support patient choice

Who Decides? emphasised 'doctor/patient dialogue'.[232] This could resolve fears that some patients are pressurised by relatives into refusing treatment.[233] The 'fair innings' argument suggests that the old are under a duty to die. Presumably, the Code of Practice that will accompany legislation will address this.[234] In general, *Making Decisions* fails to support patient autonomy as extensively as expected. The government recognises that the common law permits advance refusals of treatment[235] hence it concludes legislation regarding advance directives is unnecessary to protect patient rights.[236] *Who Decides?* questioned whether previous proposals that doctors should incur no liability for failing to comply with advance refusals of treatment struck an 'appropriate balance' between doctors and patients.[237] Bernat believes that there may be cases where advance refusals

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[219]Law Commission. *Mental Incapacity.* (Consultation Paper 231) 1995 HMSO, London. Law Commission. *Mentally Incapacitated Adults and Decision-Making: An Overview* (Consultation Paper No 119) 1991 HMSO, London and Law Commission. *Mentally Incapacitated Adults and Decision-Making: A New Jurisdiction*; *Mentally Incapacitated Adults and Decision-Making: Medical Treatment and Research; Mentally Incapacitated and Other Vulnerable Adults: Public Law Protection.* (Consultation papers No 128, 129, 130) 1993 HMSO, London.

[220]House of Lords Select Committee on Medical Ethics Report 1993-4 HL21-I HMSO, London.

[221]Lord Chancellor's Department. *Who Decides? Making Decisions on Behalf of Mentally Incapacitated Adults.* (Cm 3803) December 1997 The Stationery Office, London.

[222]Ibid, paras 1.5 and 2.19 - 2.24.

[223]*Who Decides*? op cit, n221, paras 2.2 and 2.3.

[224]Lord Chancellor's Department. *Making Decisions* (Cm 4465) October 1999The Stationery Office, London.

[225]Ibid, para 7 at p2.

[226]Royal Assent was received 9 May 2000. Implementation of the Act begins April 2001.

[227]This mirrors the Adults with Incapacity (Scotland) Act 2000 s1(6).

[228]*Making Decisions* op cit, n224, para 12 at p3.

[229]Ibid, para 18 at p4.

[230]Ibid, para 8 at p2.

[231]Ibid, paras 4.34 and 4.37.

[232]*Who Decides*? op cit n221, para 4.18.

[233]Ibid, para 4.23.

[234]*Making Decisions*, op cit n224, para 22 at p5.

[235]Ibid, paras 16 - 20 at p4.

[236]Ibid, para 20 at pp3-4.

[237]*Who Decides?* op cit n221, para 4.30.

should not survive supervening incapacity because the incompetent patient's life is painfree and apparently happy therefore experiential interests should over-ride the critical interests embodied in self-determination.[238] Similarly, Degrazia argues that the person who exists after the loss of capacity is a different person from the one before therefore decisions made prior to incapacity are not binding.[239] Arguments like this encourage doctors to ignore advance directives. There is no mention in *Making Decisions* of the decision in *St George's*[240], although *Who Decides?* treated pregnant women differently from other patients by suggesting that advance refusals of treatment should only be respected if the risk of death and acknowledgement of pregnancy are made.[241] It seems more appropriate for the elected representatives of the public to decide whether prior refusals will always be binding rather than doctors.

7.3.2.2 Incapacity and Best Interests

Making Decisions advocates a presumption in favour of capacity[242] and rejects the concept that capacity depends on rationality.[243] A statutory definition of incapacity is proposed based on the functional ability of the decision-maker.[244] Patients who are unable to communicate decisions will be deemed incapable.[245] This leaves patients with impaired communication abilities vulnerable to the vagaries of doctors and the resource-strapped NHS since the government has merely 'noted' the Law Commission's emphasis on taking 'all practicable steps' to enable patients to communicate their decisions.[246] It is unlikely mechanical communication aids will be available to many although the Scottish Act contains a proviso that no one should be deemed incapable because of a remediable inability to communicate.[247] The determination of incapacity in the Scottish Act is similar to that proposed in *Making Decisions*. Hence the form English legislation would adopt could be that 'incapable means incapable of (a) acting; or (b) making decisions; or (c) communicating decisions; or (d) understanding decisions; or (e) retaining the memory of decisions...'.[248] The consultation paper on Mental Health legislation examined the concept of 'best interests' briefly. The Scoping Committee identified a choice regarding what constitutes a patient's 'best interests' between a model prioritising 'the professional opinion of the clinical team' and one prioritising 'the presumed wishes of the patient as far as they are ascertainable'.[249] The government prefers the former which is contrary to the strong emphasis placed upon patient rights by many ethicists.[250]

The 'best interests' approach is preferred to substituted judgment.[251] As the point is not discussed, it seems that the 'best interests' approach will be used with vegetative patients although *Who Decides?* queried whether this

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[238]Bernat E. The living will: does an advance refusal of treatment made with capacity always survive any supervening incapacity? *Medical Law International* 1999;**4:**1-21 at p9.
[239]Degrazia D. Advance Directives, Dementia and the 'Someone Else Problem'. *Bioethics* 1999;**13,**5:373-391.
[240]*R v St George's Healthcare NHS Trust, ex parte S.* [1998] 2 FLR 728.
[241]*Who Decides?* op cit n221, paras 4.26-4.29.
[242]*Making Decisions*, op cit n224, para 1.1 at p7.
[243]Ibid, para 1.9 at p8.
[244]Ibid, para 1.6 at p8.
[245]Ibid.
[246]Ibid, paras 1.7 and 1.8 at p8.
[247]The Adults with Incapacity (Scotland) Act 2000 s1(6).
[248]Ibid.
[249]Department of Health and Welsh Office Expert Committee (Richardson G, Chair). *Review of the Mental Health Act 1983: Draft Proposals for the New Mental Health Act.* April 1999 Department of Health and Welsh Office, London at para 174.
[250]Secretary of State for Health. Reform of the Mental Health Act 1983: Proposals for Consultation. (Cm 4480) November 1999, The Stationery Office, London.
[251]*Making Decisions*, op cit n224, para 1.10 at p8.

criteria should be set aside in such cases.[252] Statutory guidance is proposed which adds to the Law Commission's list of factors[253] the additional factors of whether the person is likely to recover capacity in the foreseeable future and checking whether prior expressed wishes were the product of duress.[254] *Who Decides?* favoured 'informal' decision-making whenever possible subject to the 'reasonableness' threshold.[255] Legislation will introduce a 'general authority to act reasonably'[256] subject to certain restrictions.[257] Actions will not attract civil liability providing they are reasonably believed to be in the person's best interests.[258] *Who Decides?* suggested that the 'general authority' should not include a right to coerce or confine incompetent adults.[259] It also upheld patient civil liberties because threats of 'going to the courts' were to be outlawed but *Making Decisions* is silent on this point.[260] The Scottish Act does restrict the use of force and detention.[261] No guidance is given regarding testing 'reasonableness'. It seems as if negligence actions could lie against doctors who fail to consult as per accepted guidance.[262] There is no provision for a statutory list of nearest relatives who should be consulted such as that found in mental health legislation.[263]

The Scottish Act provides for doctors to certify that a patient lacks capacity.[264] The certificate can last for a year and is renewable.[265] It confers authority for the doctor in charge to do 'what is reasonable in the circumstances...to safeguard or promote the physical or mental health of the patient.[266] *Making Decisions* is likely to be similar. The form of treatment offered remains a clinical matter.[267] It is probable that there will be restrictions to prevent abuse of clinical power.[268] *Who Decides?* proposed a new offence of ill-treating or wilfully neglecting a person.[269] This appears in the Scottish Act.[270] *Making Decisions* states that the government was not persuaded that a new offence would tackle abuse.[271] Introducing a new offence could dilute the checks currently imposed by the criminal law. Dr Arthur was charged with attempted murder.[272] Doctors in future could face a lesser charge of wilful neglect with lesser sanctions attached.[273]

7.3.2.3 Proxy decision-makers

Making Decisions proposes introducing a Continuing Power of Attorney system to enable proxy decision-making.[274] *Who Decides?* suggests that children of sixteen years and above are to be treated as adults.[275] The

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[252] *Who Decides?* op cit n221, para 5.30.
[253] *Making Decisions,* op cit n224, para 1.11 at p9.
[254] Ibid, para 1.12 at p9.
[255] *Who Decides?* op cit n221, paras 3.26-3.28.
[256] *Making Decisions,* op cit n224, para 1.16 at p10.
[257] Ibid, para 1.23 at pp10-11. For example, giving consent to marriage is excluded.
[258] Ibid, para 1.17 at p10.
[259] *Who Decides?* op cit n221, para 3.41.
[260] Ibid, para 3.24.
[261] Adults with Incapacity (Scotland) Act 2000 s47(7).
[262] A point considered in *Who Decides?* op cit n221, para 3.24.
[263] See: the Mental Health Act 1983 s26.
[264] Adults with Incapacity (Scotland) Act 2000 s47.
[265] Adults with Incapacity (Scotland) Act 2000 s47 ss5-6.
[266] Adults with Incapacity (Scotland) Act 2000 s47(2).
[267] *Who Decides?* op cit n221, para 2.5.
[268] As in Adults with Incapacity (Scotland) Act 2000 s47(8)-(10), and ss48-50.
[269] *Who Decides?* op cit n221, para 3.48.
[270] Adults with Incapacity (Scotland) Act 2000 s83.
[271] *Making Decisions*, op cit n224, para 1.37 at p12.
[272] *R v Arthur* (1981) 12 BMLR 1.
[273] The maximum sentence under the Adults with Incapacity (Scotland) Act 2000 s83 will be two years imprisonment.
[274] *Making Decisions*, op cit n224, para 2.4 at p14.
[275] *Who Decides?* op cit n221, para 1.14.

Scottish Act adopts this proposal.[276] Yet *Making Decisions* proposes that only those over eighteen years will be able to appoint an attorney.[277] This leaves the estranged or parentless child unable to select his/her own proxy even in the event of foreseeable incapacity. As with the Scottish Act, the form for making a CPA will be prescribed and will be more arduous than standard will-making.[278] Unless the procedure is well-publicised, patients may not realise that they need to be certified competent at the time of creation. The power must be registered before use.[279] It will be important to avoid excessive administrative delay, particularly where court-appointed managers will be needed.[280] Decisions by the attorney will be treated as if made by the adult.[281] *Making Decisions* does not answer the concern raised in *Who Decides?* that attorneys could veto treatment doctors believed appropriate but could not prevent the withholding treatment of treatment.[282] Presumably, conflicts would fall to the Court of Protection to resolve[283] even though the Law Society believes it is unsuitable in its present from.[284] With any advance decision-making, continuing powers of attorney, or appointment of proxy a risk exists that the patient's views may have changed. Most proxy decision-makers have less understanding of ethical and medical issues than doctors or courts. The courts will be able to revoke a CPA if the attorney is unsuitable or is not acting in the patient's best interests.[285] The conservative approach taken by the government possibly reflects a view that respect for autonomy requires respect for the human being rather than mere respect for a past statement of choice.[286]

In *Who Decides?* the government questioned how realistic it is to expect proxy decision-makers to place the patient's interests before their own or those of others they are close to.[287] This question is unanswered but there will be a general authority to 'act reasonably'.[288] The burden on others may be a reasonable consideration. Religious or cultural factors[289] will be 'factors the person would consider'.[290]

7.3.2.4 The Role of the Courts

Who Decides? questioned the role and powers of the courts.[291] It suggested that certain treatment decisions should continue to be subjected to independent scrutiny.[292] The use of 'second medical opinion' was suggested as a way to make treatment decisions, possibly even for withdrawing artificial nutrition from vegetative patients despite the opportunity for misuse.[293] *Making Decisions* proposes that 'certain serious healthcare decisions' will remain matters for the courts.[294] The Scottish Act simply provides for Ministers to exclude certain treatments from the authority to treat.[295] It seems that judicial scrutiny of medical decisions will be the

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[276]Adults with Incapacity (Scotland) Act 2000 s1(6).
[277]*Making Decisions*, op cit n224, para 2.4 at p14.
[278]Ibid, para 2.10 at p15.
[279]Ibid, paras 2.14-2.15 at p16.
[280]Provision will be made for emergency situations: *Making Decisions*, op cit n224, para 2.20 at p17.
[281]*Making Decisions*, op cit n224, para 2.25 at p17.
[282]*Who Decides?* op cit n221, paras 5.6 and 5.7.
[283]*Making Decisions*, op cit n224, para 3.4 at p19.
[284]The Law Society. *Response to 'Who Decides?'* www.lawsociety.org.uk/dcs accessed 6 March 1999.
[285]*Making Decisions*, op cit n224, para 2.22 at p17.
[286]For this argument, I acknowledge my indebtedness to Luke Gormally: Gormally L. *Legislating for Advance Refusals of Treatment: What is at issue?* 1998 Linacre Centre, London www.linacre.org/advdirec.html.
[287]*Who Decides?* op cit n221, para 3.24.
[288]*Making Decisions*, op cit n224, para 1.15 at p9.
[289]*Who Decides?* op cit n221, para 3.24.
[290]*Making Decisions*, op cit n224, para 1.11 at p9.
[291]*Who Decides?* op cit n221, paras 7.1- 7.16.
[292]Ibid, paras 5.1 - 5.34.
[293]Ibid, paras 5.16 - 5.22, 5.27 and 5.28.
[294]*Making Decisions*, op cit n224, para 3.8 at p20.
[295]Adults with Incapacity (Scotland) Act 2000 s48.

exception rather than a necessary rule in order to protect the most vulnerable members of society from invasions such as sterilisation by hysterectomy which is not specifically mentioned in *Making Decisions*. Having noted the tension between the preventing of incompetent adults from donating blood on ethical grounds and the sanctioning of bone marrow donation from such adults by the courts[296] the government's failure to demonstrate strongly that the vulnerable should be protected from undue interference suggests that it believes all individuals should contribute to the welfare of society in a positive way and certainly should not unnecessarily burden it.[297]

Who Decides? rejected the concept of an administrative tribunal to deal with healthcare matters despite the attractiveness of its informality because the courts already have the necessary resources and expertise[298] and because, sometimes, issues other than medical treatment may require consideration.[299] A new Court of Protection will handle these issues.[300] To many, the involvement of the courts carries stigma and, although the Court of Protection already uses an 'informal and inquisitorial approach',[301] it does not currently make healthcare decisions so the objection that a new forum would have to develop expertise in these matters applies just as strongly.[302] Further, the proposal to separate decision-making for children under sixteen from those over sixteen and adults will dilute present judicial expertise.[303] The narrow selection of judges who have this expertise would be made even narrower if they were divided between adult courts and children's courts. It is also worth noting that the ages of the children involved in *Re M*[304] and *Re E*[305] were stressed in the judgments.

It is regrettable that other alternatives to the courts were not considered such as hospital ethics committees, or 'prognosis boards' which are sometimes used in the U.S.A. to allow non-compulsory, impartial discussion of different issues in individual cases.[306] Relatives can participate in these and a casuistic approach is taken with the physician and family representative(s) examining the clinical evidence and determine whether, or how aggressively, treatment should continue.[307] Several authors consider them beneficial.[308] However, care is needed to ensure illegitimate issues are not considered when reviewing individual cases. For instance, Thornton and Lilford consider that 'particular beneficiaries' of these committees are the 'third parties who may be affected by a patient's decision'.[309] They suggest that it may be appropriate to act paternalistically since some 'patients may be pleased in the long run if the committee's experience stops them harming themselves or others'.[310] In contrast, Campbell and McHaffie favour 'multidisciplinary' groups over ethics committees since they can provide 'ethical comfort and...legal protection' and, as good multidisciplinary practice develops, the need for formal fora would diminish.[311] This is grounded in the 'responsible body of medical opinion' approach. Such groups can help develop good practice but it seems they may be as short-lived as some of the

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[296] *Who Decides?* op cit n221, para 5.13.
[297] See also, *Who Decides?* op cit n221, paras 5.31 - 5.34.
[298] Ibid, para 9.4.
[299] Ibid, para 9.5.
[300] *Making Decisions*, op cit n224, para 3.4 at p19.
[301] *Who Decides?* op cit n221, para 9.4.
[302] A point which is weakly acknowledged in para 9.17.
[303] *Making Decisions*, op cit n224, para 4.13 at p30.
[304] *Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097 (15 and a half years old).
[305] *Re E (A Minor)(Wardship: Medical Treatment)* [1993] 1 FLR 386 (15 years, 9 months).
[306] Barnett TJ. Are there employment risks to ethical decisions? *Nursing Forum* 1993;**28**,1:17-21.
[307] Ibid, at p17.
[308] Moss AH et al. Variation in the Attitudes of Dialysis Unit Medical Directors Towards Decisions To Withhold and Withdraw Dialysis. *J.Am.Soc.Nephrology* 1993;**4**:229-234. Also; Rosner F. Hospital medical ethics committees: a review of their development. *JAMA* 1985;**253**:2693-7.
[309] Thornton JG, Lilford RJ. Clinical ethics committees. *BMJ* 1995;**311**:667-9.
[310] Ibid, at p669.
[311] Campbell AGM, McHaffie HE. Prolonging life and allowing death: infants. *J.Med.Ethics* 1995;**21**:339-344 at p342.

patients for whom they make decisions.[312]

7.3.2.5 The usefulness of the proposals

Overall, whilst government intervention has been viewed as long overdue by the courts, there is a danger that new legislation may lack cohesiveness with a plethora of decision-makers supplementing and replacing existing ones and variability of decision-making criteria depending on the patient. The government's proposed legislation shows increasing support for autonomy as a guiding principle in healthcare decision-making. However, issues such as openness on the part of doctors are not addressed. Only if doctors are prepared to truthfully disclose treatment options and outcomes can the attorney or the court make the best decision for the patient. The popularity of 'futility' arguments has increased with the rise in cost constraints.[313] Pressure upon beds and other resources means 'futility' may be mis-used when advising attorneys. *Making Decisions* fails to address the issue of resource constraints and how to allocate scarce resources in a way that balances individual interests against societal interests.

7.4 Recent Ideas from the Legal Profession and Others

7.4.1 Addressing Issues of Distributive Justice

In1996, Dworkin suggested the 'prudent insurance principle' as a method to answer the joint questions, how much to spend and what healthcare to buy.[314] He has now developed this in more detail.[315] Dworkin argues that current expenditure is based on the belief that health differs from other 'goods' so equality of access is essential.[316] Secondly, the 'rescue principle' is constantly evoked so that whatever can be done to avoid death is held to be necessary care.[317] Dworkin suggests that 'no sane society'[318] would allocate resources to cases like *ex parte B.*[319] However, he accepts that the rescue principle is useful in holding that if rationing is necessary it should be carried out on the grounds of need not money.[320] Dworkin rejects the idea that greater efficiency avoids rationing because the efficiency model disguises rationing by eliminating 'low yield' treatments.[321] Dworkin argues that the key is to imagine a world where wealth is evenly distributed, all possible information about treatments is available to the public not just doctors, and no one knows 'how likely any particular person is to contract a particular disease or suffer any...accident'.[322] In this world, even if money was freely available to all, Dworkin believes that few would buy health insurance that offered life-saving treatment if they fell into a persistent vegetative state.[323] Dworkin believes that whatever his 'transformed community' decides to allocate to healthcare is non-criticisable since the amount will be 'morally appropriate'[324] and however the healthcare

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[312]Larcher VF, et al. Paediatrics at the cutting edge: do we need clinical ethics committees? *J.Med.Ethics* 1997;**23:**245-9.
[313]Carnevale FA. The Utility of Futility: The Construction of Bioethical Problems. *Nursing Ethics* 1998;**5,**6:509-515 at p512.
[314]Smith R. Being creative about rationing. *BMJ* 1996;**312:**391-2.
[315]Dworkin R. *Sovereign Virtue: The Theory and Practice of Equality.* 2000 Harvard University Press, London. See, in particular, chapter 8 'Justice and the High Cost of Health' at pp307-319.
[316]Ibid, at p309.
[317]Ibid.
[318]Ibid.
[319]*R v Cambridge District HA, ex parte B* [1995] 1 FLR 1055. Dworkin's reference to the Child B case was reported in Smith R. Being creative about rationing. *BMJ* 1996;**312:**391-2 at p312 but does not specifically appear in *Sovereign Virtue*.
[320]Dworkin, op cit n315, at p310.
[321]Ibid, at p308.
[322]Ibid, at p312.
[323]Ibid, at p313.
[324]Ibid, at p312.

is distributed will be 'just for that society'.[325] There would be three levels of provision: care that almost everyone agreed was necessary; care that almost everyone agreed was unnecessary and care where people chose differently. Dworkin argues that the state could fund the first level but not the second and people could take out private insurance for the third level if wished. His 'prudent insurance test' asks what cover individuals would pay for, then 'insists' that, as a nation, 'aggregate expenditure' should meet this level so that all have that level of cover.[326] Dworkin suggests that the guidelines developed by NHS doctors are based partially on the concept of prudent insurance.[327] The 'what would I want for my mother, my sister...' style of reasoning may reflect this.[328] However, Dworkin has not addressed how to get the agreement on the first two levels other than by consulting the public.[329] One criterion is that there is full knowledge (about effectiveness of treatments) yet another criterion is that there is no knowledge (about gender, cultural or societal predispositions to disease).[330] Yet the former level of knowledge necessitates having the knowledge he denies anyone should have. Gender, societal and cultural qualities have implications for disease prognosis and management. This model does not address the social problems that would arise if many people felt they needed the third level of care but could not afford it. If such division of funding meant that state-run hospitals only provided state-funded treatments and private hospitals were the only place for the privately-insured treatments, medical expertise may end up concentrated in the private sector with state-funded treatments becoming the new 'Cinderella' services.[331] Finally, Dworkin's model pays inadequate regard to whether there is an ethical requirement to treat, or not to treat, certain conditions or whether certain treatments are less ethically acceptable than others.

7.4.2 Improving the Individual Patient Decision-making Process

Jonsen has described a casuistic model of decision-making.[332] Some judges also have recently adopted this approach to decision-making. For instance, the Churchillian list employed in *Re A* has casuist origins.[333] In the conjoined twins case, Walker LJ said, 'The term 'casuistry' has come to have bad connotations but the truth is that in law as in ethics it is often necessary to consider the facts of the particular case, including relevant intentions, in order to form a sound judgment.'[334] Beauchamp and Childress suggest its disrepute rivalled that of astrology.[335] In medical decision-making it is increasingly necessary to ascertain the facts of particular cases and ascertain why people appear to be making certain decisions. Under the scientific model of decision-making, facts are more relevant than experience and intuition. The doctor's motive or intention is as relevant as the patient's or the family's. Certain intentions are clearly wrong, sometimes unlawful, but in other cases, only when there has been openness on the part of those involved with making the decision can its soundness be confirmed. Nelkon rightly notes that '(r)elying upon the parties to bring forward their evidence sets severe limits to the nature of legal enquiries'.[336] This is why it was such an important advance for the Court of Appeal in the conjoined twins case to seek independent medical advice. As McHale points out, the use of the amicus

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[325]Ibid, at p313.
[326]Ibid, at p317.
[327]Ibid, at pp317-318.
[328]See discussion in earlier chapters of this thesis.
[329]Dworkin, op cit n315, at p318.
[330]Ibid, at p312.
[331]A spectre raised by Tony Blair recently: Miles A. Can the NHS be Saved? Last Chance. *The Times* 26 May 2000.
[332]Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine.* 4th Edn. 1998 McGraw Hill, New York.
[333]*Re A (Male Sterilisation)* [2000] 1 FLR 549.
[334]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 at p117F.
[335]Beauchamp TL, Childress JF. *Principles of Biomedical Ethics* 4th Edn. 1994 Oxford University Press, Oxford at p93.
[336]Nelkon D. 'A just measure of science'. In Freeman M, Reece H (Eds). *Science in Court* 1998 Ashgate, Aldershot pp11-36 at p19.

curiae brief is still not as extensive as it could be.[337] Many patients and families are denied independent advice even if their case is subjected to judicial scrutiny.

The empirical evidence obtained for this thesis found that doctors did not utilise the Beauchamp and Childress four principles (autonomy, beneficence, non-maleficence and justice) when making decisions.[338] Although it could be argued that they were wrong not to do so, attempts to improve decision-making must acknowledge this fact. Jonsen et al's model is designed to give clinicians 'a straightforward way to sort out the facts and values of the case at hand into an orderly pattern that will facilitate the discussion and resolution of the ethical problem'.[339] Whilst recognising the value of the principled approach to decision-making, Jonsen et al point out that often there is a 'wide range of medical facts, a multitude of circumstances, and a variety of values'.[340] These may remain hidden and the decision-making process distorted unless a policy of openness is adopted. The analysis involves four topics: medical indications; patient preferences; quality of life and contextual features.[341] Medical indications include identifying the patient's medical problem, past history, diagnosis, whether the problem is acute or chronic, emergent or reversible, what the goals of treatment are, what the prognosis is, what can be done if therapy fails, how the patient can be benefited by treatment and how harm can be avoided.[342] Different treatment options should be identified not simply the ones that are available to the doctor or the ones the doctor is prepared to offer the patient.[343] This does not mean patients should be confused with a variety of choices but it means the doctor can offer the most appropriate choice(s) when patient preferences, in particular, are in opposition to possibly the most effective clinical option. This avoids situations such as *Re C* where the choice offered the patient was amputation or death.[344] Once the court held that his preferences could prevail, alternative therapy was sought and the leg saved. Patient preferences include identifying whether the patient has expressed (now or in the past) any preferences about treatment; whether the patient has been informed of benefits and risks and given consent; whether the patient is competent or will regain competence in the near future; the willingness, or ability, of the patient to co-operate with treatment and to what extent legally and ethically possible is the patient's right to choose being respected.[345] Quality of life involves examining the prospects, with or without treatment, for a return to the patient's normal life, whether there are any biases that might prejudice the healthcare provider's evaluation of the patient's quality of life, what physical, mental and social deficits the patient is likely to experience if treatment succeeds, whether the patient's present or future condition is such that continued life might be judged undesirable by him/her, whether there is any plan or rationale for forgoing treatment and what care and comfort can be given if a non-treatment option is chosen.[346] Jonsen highlights the distinction between personal evaluation of quality of life and observer evaluation.[347] The contextual features involve examining whether there are family issues that might influence treatment decisions, whether there are physician or nurse issues that might influence treatment decisions, whether there are economic, religious or cultural factors, whether there is any justification to breach confidentiality, whether there are resource allocation constraints, what the legal implications of the treatment/non-treatment decision are, whether clinical research or teaching is involved and whether there is

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[337]Fox M, McHale J. In Whose Best Interests? *Mod.Law Rev.* 1997 Sept: 700-709 at p709.
[338]Beauchamp TL, Childress JF. *Principles of Biomedical Ethics.* 4th Edn. 1994 Oxford University Press, Oxford.
[339]Jonsen et al, op cit n332 at p2.
[340]Ibid.
[341]Ibid.
[342]Ibid, at p13.
[343]Ibid, at p18 and p140.
[344]*Re C (Adult: Refusal of Medical Treatment)* [1994] 1 WLR 240.
[345]Jonsen et al, op cit n332, at p13.
[346]Ibid.
[347]Ibid, at p110.

any provider or institutional conflict of interest.[348] Together, the four topics 'organise the varying facts of the particular case and...call attention to the moral principles appropriate to the case'.[349]

One of the advantages of the model is that the four boxes (one for each topic) can be drawn on a whiteboard or piece of paper and completed as fully as possible. It can help identify whether any other information is necessary in order to make a sound decision. This mirrors Devettere's 'situational awareness'.[350] Another advantage is that the decision-making process avoids the normative nature of principlism which creates 'an ethics of obligation'[351] and instead has a greater emphasis on the individual patient 'living well'.[352] Ultimately, probably each of us wants medical decisions to be centred upon ourselves even though we can recognise that society places certain obligations upon its individual members. Many of the conflicts that have to be resolved by the courts arise because there is doubt over whether the decision will enable the individual to 'live well' or because the individual patient (or his or her supporters) believe that what is appropriate is being denied due to resource constraints.

Obviously, the ethical values embedded in the principled approach that is popular in Anglo-American bioethics are present in the Jonsen model. One of the problems with the principled approach is that 'when they conflict we have to balance them against each other to determine which one prevails and becomes our absolute obligation in the particular situation'.[353] This balancing approach is becoming more popular in English medico-legal cases.[354] Consequently, the principle of autonomy seems to be weighted more highly than other principles where the patient is competent and there is no threat to public health or values. However, ethics is more than 'the safeguarding of mere personal preferences'.[355] At times, different ethical values have to be balanced against each other. As the conjoined twins case shows, there is no obvious way to do this: one of the three judges held that it was in Mary's best interests to have 'bodily integrity' even though this meant death.[356] There is also little scope within the principled approach to take into consideration other factors. Principle-based ethics can be seen as 'removed from the real work and content of ethics'.[357] The Jonsen model seeks to identify all factors affecting the decision-making process since only by being open and identifying them can the legitimacy or otherwise of each of these be determined. Thus it avoids the criticism that '(c)asuists have no clear methodological resource to prevent...a neglect of relevant features of cases'.[358] However, over-emphasis on the circumstances of individual cases could lead to fragmentation and inconsistency in the model's usefulness in guiding 'everyday life and social policy'.[359] Hence, to work successfully, the casuist approach must be one that attends to 'the particulars' as well as be sympathetic to the universal principles.[360]

The Jonsen model is not without its flaws. The 'topics' embrace Beauchamp and Childress principles.[361]

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[348]Ibid.
[349]Ibid, at p2.
[350]Devettere, RJ. *Practical Decision Making in Health Care Ethics: Cases and Concepts.* 1995 Georgetown University Press, Washington DC.
[351]Ibid, p23.
[352]Ibid, pp18-21.
[353]Ibid, p23.
[354]See: *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 and *Re A (Male Sterilisation)* [2000] 1 FLR 549.
[355]Kuczewski MG. *Fragmentation and Consensus: Communitarian and Casuist Bioethics.* 1997 Georgetown University Press, Washington DC at p2.
[356]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 at p119F per Walker LJ.
[357]Kuczewski, op cit n355, at p60.
[358]Beauchamp TL, Childress JF. *Principles of Biomedical Ethics* 4th Edn. 1994 Oxford University Press, Oxford at p97.
[359]Kuczewski, op cit n355, at p66.
[360]Ibid.
[361]Beauchamp TL, Childress JF. *Principles of Biomedical Ethics.* 4th Edn. 1994 Oxford University Press, Oxford.

Hence, patient preferences broadly equates to autonomy. Some of the contextual features are related to the principle of justice. There is evidence of beneficence and non-maleficence within both the medical indicator topic and the quality of life topic. But the quality of life topic also suggests that questions that may relate to autonomous choice are asked. The goals of treatment can only be assessed by the patient in terms of the risks, benefits and costs of treatment as Jonsen et al recognise.[362] The cultural and religious factors identified within contextual features could be seen as belonging more appropriately to patient preferences. Hence they are entwined with patient preference. The provider issues that might influence treatment decisions perhaps belong more appropriately with medical indicators. Breach of confidentiality belongs better with patient preferences. Consequently, the approach seems somewhat muddled although it is fundamentally correct in promoting openness. Jonsen et al fail to advise how what to do when patient preferences clash with medical indications or when contextual issues, such as the likely burden on the family once the patient is discharged from hospital, mean that, although treatment could be successful in returning the patient to his or her 'normal' standard of life, it would be better for the family not to treat. In the case of David Glass, the doctors believed they were acting in his best interests.[363] As a non-autonomous patient who had never had, or would have, the ability to express preferences, treatment decisions are to be made in his best interests. The principles of beneficence and non-maleficence outweigh autonomy. The Jonsen model may have made them question whether there were biases that prejudiced their evaluation of his quality of life. If the decision to give diamorphine and palliative care only had been made after following a Jonsen-style analysis the doctors would presumably have felt the medical indicators and his quality of life prior to admission outweighed family wishes. The question remains, why should one balancing process be better than another. The answer must be that the casuistic model suggests greater openness than seems to occur with other approaches. Ultimately, the greatest value of evidence gathering, as advocated by Cochrane,[364] is 'to estimate the probability for outcomes that matter to patients and to elucidate the importance of patient preferences in choosing treatment'.[365] Then it is possible to identify what is appropriate and proportionate treatment.[366] This needs to occur within a 'stable framework of general norms' so as to provide controlled judgment and prevent 'prejudiced or poorly formulated social conventions'.[367] Such an approach can be seen in the conjoined twins case where it was held that 'the rule of proportionality is central to the evaluation of a justification premised on two conflicting duties'.[368] In that case, '(t)he actions of the doctor viewed objectively constitute(d) a proportionate and necessary response to the competing interests viewed as a whole'.[369] The doctors owed 'conflicting legal (not merely social or moral) duties' but 'the test of proportionality' was met.[370] The challenge casuistry must face is that without safeguards in its use, it could 'degenerate into mere sophistry or become an apology for the status quo'.[371]

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[362]Jonsen et al, op cit n332, at p19.
[363]*R v Portsmouth NHS Trust, ex parte Glass* [1999] 2 FLR 905.
[364]Cochrane AL. *Effectiveness and Efficiency.* 1972 Nuffield Provincial Hospitals Trust, London.
[365]Jonsen et al, op cit n332, at p19 citing Wennberg JE (1996).
[366]Ibid, at pp138-140.
[367]Beauchamp TL, Childress JF. *Principles of Biomedical Ethics* 4th Edn. 1994 Oxford University Press, Oxford at p997.
[368]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 at p59G per Ward LJ.
[369]Ibid, at p77C per Brooke LJ.
[370]Ibid, at p115F per Walker LJ.
[371]Kuczewski, op cit n355, at p68.

7.4.3 Improving the Decision-making Process Relating to Incompetent Patients

Listening to Children's Views[372] is a report on the extent to which children's voices and opinions are heard when parents are undergoing legal, administrative and mediatory processes relating to family breakdown. Many of the recommendations are relevant for healthcare, not just regarding children, but also adult patients particularly those with learning disabilities.[373] As O'Quigley says, 'all children have a right to be listened to about matters that affect their lives'.[374] Patients with impaired or fluctuating capacity have the same right.[375] Three major themes are identifiable. First, autonomy and enhancing the child's ability to make his or her own decisions; second confidentiality and third, the need for cultural and developmental sensitivity.[376]

7.4.3.1 Autonomy

The O'Quigley report makes a number of key recommendations relating to autonomy:

- Adults should allow children to tell the whole of their story without interrupting or rushing to interpretation.
- Adults should adopt a non-intrusive style of interviewing with the aim of learning from the child.
- Adults should be open-minded and non-judgmental, and allow the child to raise his/her agendas and not simply respond to the adult agenda.
- Good communication is more likely to occur if adults see children's abilities and competencies as being *different* from rather than *lesser* than adults'.
- Questions should be simple and direct; indirect questions should be avoided as these are experienced by children as 'trick' questions.
- The child needs adequate information in order to express views.
- The interviewer should be alert for any sign of distress in the child and acknowledge it.
- Younger children may prefer to speak if they have a friend with them.

Healthcare professionals need to identify barriers to the child acting autonomously.[377] These can include barriers due to the child's life experiences which possibly are not known to the healthcare team as well as barriers erected by the healthcare team, for instance, through failure to show cultural sensitivity, or isolating him or her from peers.[378] One of the biggest barriers is poor communication.[379] Allowing children to relate, without interruption or condemnation, what values they hold dear, and what factors they consider important, is highly important. Then these values and factors can be explored. For instance, in the case of *Re L*, a strongly motivating factor for refusing treatment could have been fear of scarring and unattractiveness to

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[372]O'Quigley, A. *Listening to Children's Views: The Findings and Recommendations of Recent Research.* 2000 The Joseph Rowntree Foundation, York.

[373]Terry L, Campbell A. *Hearing Children's Voices.* Paper presented at The 3rd Annual Trevor Clay Memorial Conference: Philosophy in Nursing, Middlesex University, London 15 September 2000. See also: Terry L, Campbell A. Hearing Children's Voices: Are We Listening? *British Journal of Nursing* (forthcoming - accepted 27 February 2001). A similar set of suggestions to O'Quigley's is found in British Medical Association. *Consent, Rights and Choices in Health Care for Children and Young People.* 2001, BMA, London at pp101-103.

[374]O'Quigley, op cit n372, at p33.

[375]Bray, DL, Ensley, MD. Dealing with the mentally incapacitated client: the ethical issues facing the attorney. *Family Law Quarterly* 1999;**33**,2:329-348 at p337.

[376]Ibid, ppvi-vii.

[377]Hollen PJ, Brickle BB. Quality Parental Decision-Making and Distress. *J. Paediatric Nursing* 1998; **13**,3:140-150.

[378]Barker P. Reflections on caring as a virtue ethic within an evidence-based culture. *International J.Nursing Studies* 2000;**37**:329-336.

[379]See earlier comments from the consultant interviewees.

boys.[380] She may also, or alternatively, believe she must adhere to the religious beliefs of the Jehovah's Witness faith she has been raised in or that she must obey her parents. Exploring all the reasons why patients are opposed to treatment, giving reassurance and answering questions honestly may lead to different decisions being made.

No patient wishes to be patronised. O'Quigley believes it is important to value children's abilities and competencies.[381] Whilst children's abilities to comprehend and interpret information and their competency in decision-making differs from adults, it is not necessarily of a lesser quality.[382] Just because a child may make a decision in an apparently less rational, or less logical manner from an adult, this does not make the decision wrong. The decision itself may be the right one for the child. It may just be that the child lacks the language to dress it in the same way adults would. Consequently, children are easily held incompetent when major decisions have to be made. O'Quigley notes the findings of others that many adults, including judges and presumably doctors, confuse 'participation' with decision-making.[383] Adults may also fear upsetting children and fear acknowledging their own vulnerabilities so they act 'as if adults know children's best interests better than they do'.[384] Adults may wish to protect children.[385] *Listening to Children's Views* gives strong support to children's rights not just under the United Nations Convention on The Rights of the Child which holds that children have rights to information; to express views including views that might influence adult decisions or complicate matters and to make decisions but as a matter of good practice.[386] O'Quigley notes that most Department of Health information leaflets for children are written for children with reading ages of fourteen years yet many cannot read at this level.[387]

A relevant factor is the computer literacy of children. As O'Quigley found, today's children like the apparent neutrality and ease of accessing information that the internet provides.[388] Left to conduct their own searches, children may access information of dubious quality and neutrality because they lack the necessary knowledge to identify poorly researched and presented information. Helping children to access accurate and appropriate information through the internet seems vitally important. The better informed the child is, the more weight can be given to his or her views although children should not be abandoned to make decisions alone.[389] However, where the child wishes to be involved, s/he has a right to expect that the healthcare professionals involved will do all they can to ensure that she or he has the information and assistance necessary to participate.

There needs to be more effective representation for children involved in judicial proceedings.[390] O'Quigley recommended that children wishing to have a friend with them should be able to do so.[391] It would be interesting to know if the child in *Re M* had a 'friend' present when interviewed by the Official Solicitor's

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[380]*Re L (Medical Treatment Gillick Competence)* [1998] 2 FLR 810.
[381]O'Quigley, op cit n372 at p29.
[382]Ibid.
[383]Ibid, at p23.
[384]Ibid.
[385]Ibid.
[386]Ibid, at pp33-34.
[387]Ibid, at p34.
[388]Ibid, at p41.
[389]Alderson P. *Children's Consent to Surgery*. 1993 Oxford University Press, Buckingham at p237.
[390]O'Quigley, op cit n372 at pvi and pp16-22.
[391]Ibid, at p29.

representative.[392] Did she feel 'interrogated'[393]? Being interviewed late at night by a stranger is potentially frightening.[394] It may be useful to be able to refer the child to a specially trained patient representative or advocate whose apparent neutrality makes him/her more acceptable to the child than members of the healthcare team. Advocates of this type have played an important role in American hospitals for twenty years.[395] The Patient Advocacy and Liason Service (PALS), announced in the NHS Plan is due to start in 2002.[396] It is unclear whether specially trained PALS will be available for children and this should be clarified.

7.4.3.2 Confidentiality

O'Quigley's list of recommendations contains one that specifically relates to issues of patient confidentiality:

- If possible, children should be assured of confidentiality; if this is not possible then the limits to confidentiality should be made clear at the outset.

Respect for persons requires that confidentiality needs to be maintained as far as possible. In many health care situations power is a key concept within the context of confidentiality.[397] Children may have a realistic or distorted view of adults' knowledge, abilities or influence. They may disclose information in the hope it will be acted on. Alternatively, they may disclose information believing it will not be passed and feel betrayed when disclosure occurs. Healthcare professionals should question their practice regarding information handling.[398] Particularly where the child's (or parent's) opposition to treatment is based on beliefs or values those caring for the child disagree with there may be a temptation to discuss the situation with others who lack the necessary training or understanding of the issues involved to assist in gaining greater insight and who themselves may not be bound by rules of confidentiality.

7.4.3.3 Cultural and Developmental Sensitivity

The O'Quigley report addresses the important issues of child development and cultural values and recommends:

- Adults should be aware of developmental and cultural factors but should beware of making assumptions about the individual child based on these.
- Some children may not want to participate in decision-making at all.

Healthcare delivery is built around an adult model rather than a child model.[399] The recent NHS Plan makes little reference to children.[400] Consequently, children find healthcare provision lacks sensitivity to their cultural and developmental needs. Children are institutionally discriminated against as a group regardless of ethnic

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[392]*Re M (Medical Treatment: Consent)* [1999] 2 FLR 1097.
[393]O'Quigley, op cit n372, at p24.
[394]Terry & Campbell, op cit n373.
[395]Mallik M. Patient representatives: a new role in advocacy. *British J.Nursing* 1997;**6**,2:108-113.
[396]Department of Health. *The NHS Plan: A plan for investment, a plan for reform.* (Cm4818-1) 2000 DoH, London. www.nhs.uk/nhsplan accessed 7 August 2000.
[397]Glen S. Confidentiality: A critique of the traditional view. *Pediatrics* 1997;**9**,15:403-406.
[398]Shardlow S. Rationality and the refusal of medical treatment: a critique of the recent approach of the English Courts. *J.Med.Ethics* 1995;**21**:162-165.
[399]Pugh G. One piece of free fruit is not enough. *The Independent* 29 September 2000.
[400]*The NHS Plan,* op cit n396.

origin.[401] In a multicultural and multi-faith arena it is important that health care professionals have self-awareness about their own attitudes and communication skills when dealing with children or families from backgrounds different to their own. Avoidable misunderstandings or unintentional offence may occur, which could have been avoided by education, consultation with relevant agencies and, most importantly, listening to children and their families as they relate both difficult and positive experiences.[402]

Language barriers present a major issue when caring for the traumatised victims of ethnic cleansing and other horrors. Interpreters may have to be employed and whilst confidentiality constraints are easily recognisable there may be less recognition that difficulties can occur if the interpreter is of a different sex from the patient. Certain apparently inoffensive terms like 'family support' may be interpreted differently in different cultural groups.[403] Familiarity with the customary styles of communication in different cultural groups, particularly when a family is experiencing grief, anxiety, fear, concern or disagreement, can enhance decision-making.[404] Over simplification of cultures (eg. 'Asian') may partially deny diversity thus enhancing the potential for stereotyping. It is important not to assume that patients will always, or perhaps ever, want to speak to a healthcare professional from the same ethnic or religious background. There may be social status, educational or value differences. This may be particularly true in sensitive areas like genetic disorders.[405] Such 'matching' may create barriers to the patient being honest about his or her real wishes and views. There may be fear of being criticised for holding values different from the ethnic community to which the patient belongs. This can be a particular problem for children who feel torn between the values of the society in which they move and are educated and more traditional values within the home. Patient's voices cannot be fully and consistently heard if healthcare professionals fail to effectively recognise different cultural and developmental requirements. Cultural sensitivity requires respecting the patient and his or her family as persons with values and beliefs which, whilst possibly different from the doctor's own, are no less important. Likewise, doctors and others should avoid assuming that children will have particular beliefs and values, or will be more likely to defer to their parents because of their cultural background. To do so would be to fail to see the child as an individual. However, some children, because of their cultural background and strong trust and belief in the role of their parents as decision-makers, may genuinely have no desire to participate in healthcare decisions. This trust should not be destroyed in order to promote 'independence' of decision-making

7.5 Conclusion

The proposals discussed above demonstrate the value of others besides doctors having an input to the debate about withholding and withdrawing medical treatment. Distributive justice, in particular, requires public input, whether this is through elected government or through other channels. It will be important to find ways to achieve this and address the concerns raised by some of the consultants regarding the value of lay input. It is for Government to decide what proportion of Gross Domestic Product is put into the NHS. This will reflect its overall vision of the sort of society it is trying to create but it was clear from the consultants' responses that continuing regional inequality is unacceptable. However, the focus on society must not exclude individual

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[401]Terry & Campbell, op cit n373.
[402]Ibid.
[403]Patterson JM, Blum RW. A conference on culture and chronic illness in childhood: conference summary. *Pediatrics* 1993;**91**,5:1025-1030.
[404]Groce NE, Zola IK. Multiculturalism, chronic illness and disability. *Pediatrics* 1993;**9**,15:1045-1055.
[405]Terry & Cedar, op cit n7.

needs. The advice doctors give patients often reflects the availability of resources. As discussed earlier, the BMA suggests that this is an acceptable part of the doctor's role but doctors lack the training and the mandate from society to do this. If, as the BMA proposes, non-treatment decisions become the sole prerogative of doctors distributive injustices will abound. The interests of the patient may be forgotten as the focus shifts to what doctors consider to be the interests of society. There is a clear need to find ways to identify when doctors can be left to decide alone and when decisions should go to independent arbitration as a final procedural step. It is also necessary to identify which inputs to the process are acceptable. The vulnerable need the courts and parliament to protect their interests for instance, by setting out procedural rules as the courts have done regarding non-therapeutic sterilisations of learning impaired women. At present, incompetent patients only receive protection if someone is prepared to challenge a non-treatment decision.

The lack of funding for palliative care, particularly for children, needs urgently rethinking. If the alternative to active treatment is poor quality palliative care, patients, parents, and doctors, may be more inclined not to opt for non-treatment. Healthcare professionals may be tempted to misuse pain-relief. Since the way healthcare is delivered affects the ability of patients to act autonomously, government, health authorities and primary care groups need to recognise that children, ethnic minorities and the learning disabled are significant users of health services. To develop services where appropriate treatment decisions can be made means listening to the views of these users which the NHS Plan consultation exercise failed to do.

Dworkin's proposals have particular merit. The government should rethink the role of NICE and the way it is currently considering treatment availabilities. The funding of the NHS lacks a sound basis since no one has identified which treatments should be provided by the state. Consequently, medical advances coupled with regional inequalities in funding have produced a healthcare lottery. Flawed public consultation exercises and politicised selection of which treatments are to be evaluated by NICE can only produce inadequate solutions to the question of whether certain treatments should be available through the NHS or withheld.

Individual decisions need to be economically, medically, ethically, legally and emotionally as sound as possible for all the parties. Many of the consultants interviewed for this thesis held similar views to those in the BMA guidance. They believe that withholding or withdrawing life-sustaining treatment is 'primarily a *medical* decision for which the doctor bears ultimate responsibility' although 'good practice imposes' a duty to note the views of nurses, other members of the team and the family.[406] However, just because this is the view of a 'responsible body of medical opinion', it is not necessarily acceptable. Many of the consultants interviewed have been qualified over twenty years and are possibly strongly influenced by the attitudes which prevailed at the time of their training. The BMA is wrong to try to secure exclusivity of the individual decision-making process. Without scrutiny and without the input of those who have expertise particularly in the fields of ethics and law, but also other fields such as statistics, psychology and training, the individual decision-making process would be likely to diminish in quality. I believe it would fail to meet the needs of the parties to the decision and gradually fail to reflect appropriate values or protect the more vulnerable members of society. Adopting the recommendations given in *Listening to Children's Voices* would improve decision-making not just for children but also for adults with reduced ability to act autonomously. It would provide a focus for training to improve communication skills which several consultants recognised as poor at present.

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[406]Campbell AGM, McHaffie HE. Prolonging life and allowing death: infants. *J.Med.Ethics* 1995;**21**:339-344 at p340. Their emphasis.

Giving competent patients the power to appoint proxy decision-makers is long overdue. This is likely to be a more acceptable way of making decisions when the patient is incompetent to both doctors and patients since it could help reduce anxieties on both sides. The government has let down the majority of the electorate by its slowness in legislating in this area. National inequality has arisen since residents of Scotland now have the power to appoint proxy decision-makers. However, the proposals found in *Making Decisions* are not ideal as they currently stand. The proposed Court of Protection, whilst it will take an inquisitorial approach, will lack the more balanced approach that a tribunal with equal input from lawyers, doctors and ethicists could achieve. As it is currently described doctors are unlikely to view it any more favourably than they do the present system. *Making Decisions* also fails to fully engage with the difficulties of ensuring that parties to decisions regarding the withholding and withdrawing of treatment are fully informed. There needs to be more openness about treatment options, success rates and the 'selling' of decisions by doctors through the way they employ terms like 'futility'. The casuistic approach that some judges have recently adopted shows commitment to openness. However, the Jonsen model fails to show how to balance the different factors once they have been identified although it is a useful tool for doctors since it can be drawn on a whiteboard for discussion. Without adequate protection, particularly for those patients who cannot speak for themselves, there is scope for the medical indicators and the doctors' estimation of the patient's quality of life to prevail over other interests. This is where ethicists, the courts and the legislature have a valuable role in identifying the interests to be protected and ways to protect or balance them when they are in conflict with each other.

Many of the conflicts that arise over the withholding and withdrawing of medical treatment occur as a result of failure to respect patients' rights to decide for themselves; or to respect patient/family preferences; or to ensure equity of outcome or equity of access to treatment, or to be honest about the necessity to ration healthcare in the NHS. Therefore, improvements to the decision-making process will need to address issues of autonomy, openness and distributive justice as well as the decision-making forum. The next chapter discusses these issues in more detail and proposes a new decision-making process.

CHAPTER 8

WITHHOLDING AND WITHDRAWING MEDICAL TREATMENT: A NEW MODEL FOR DECISION-MAKING

This chapter briefly summarises the findings of the previous chapters and restates the nature of the problems surrounding the withholding and withdrawing of medical treatment. It then discusses the concepts of autonomy, openness and distributive justice that have been identified as key factors for improving the decision-making process. Using these as foundation stones, a system to improve the decision-making process is proposed. The emphasis will be on 'ethical truth as a process rather than a result' with rights being seen as 'conditions necessary to promote inclusion in the process'.[1]

8.1 Summary of the Preceding Chapters

Chapter 2 shows that the recent history of the NHS is troubled by economic and political pressures and identifies the diverse nature of the conflicts that result because doctors are pressurised, overtly or covertly, by patients and their families, judges, other doctors, politicians and budget-holders. Chapters 3 and 4 demonstrate that decisions are primarily based on clinical prognosis but are flawed because the evidence-base is lacking. There is a lack of honesty over the effect of economic/resource constraints and a use of 'trump' words like 'futility' to 'sell' decisions to patients, families and judges. Patient autonomy is not always well-supported as doctors seem to decide in their own minds what treatment options they are prepared to propose to the patient and only disclose their preferred options. Decisions may be based on the social circumstances, age or disability of the patient. The way decisions to withdraw treatment are made differs from the way decisions to withhold are made thereby resulting in greater scope for value judgments when treatment withdrawal is under consideration. The wishes of the family and the burden on the family are also more relevant in withdrawal cases. Whilst ethically, there may be no difference, it would be wrong to ignore this. Chapters 2, 3 and 4 also demonstrate the emotional nature of decisions to withhold or withdraw medical treatment and the anxiety doctors have regarding non-treatment. Chapter 5 shows that there are many models bearing on the issue which seem to be isolated from each other, each proposing only a partial solution to the multifaceted problem of when to treat and when not to treat. Consequently research into what constitutes a medically, socially and ethically acceptable decision is necessary in order to discover how best to balance individual needs against societal needs. Chapter 6 demonstrates judicial support for patient autonomy and openness in decision-making. However, determinations of patient 'best interests' are strongly influenced by medical determinations of quality of life, so elderly and learning/physically disabled patients are insufficiently protected against discriminatory practices. When decision-making moves from the bedside to the courts, the change in focus from medicine to law creates tensions as each side has its own prejudices about the ability of the other to make the right decision so the validity of input from each other's discipline may be strongly resisted, as Chapter 7 demonstrates. Chapter 7 also reveals that recent proposals suffer from problems in that they do not show how to tie together all the different issues; doctors end up having to juggle patient autonomy, patient best interests,

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[1]Kuczewski MG. *Fragmentation and Consensus: Communitarian and Casuist Bioethics*. 1997 Georgetown University Press, Washington DC at p110.

family demands and the demands of their other patients. Although Klein asserts that it is 'positively undesirable'[2] to search for a set of principles that will make the decision and all that is needed is to improve the 'process' by which decisions are made,[3] it is clear that the principles of autonomy, openness and distributive justice are important in structuring that process. The decision-making process can be improved if these three principles, underpinned by anti-discriminatory practice, are given greater support by doctors, judges, healthcare purchasers and politicians. The process needs to address the complex issues of finance, law, professional conduct and ethics and, if possible, reduce the number of factors the doctor has to juggle when making individual non-treatment decisions. As Kuczewski states, 'advances in technology and changing social roles have raised problems in everyday professional life for which guidance is needed'.[4] It will also be necessary to find ways to provide emotional support for all the parties to the decision-making process, including doctors, particularly when the decision is liable to result in the death of the patient. There will never be a final, immutable answer because science, disease, populations and politics are not static, but better decision-making is possible.

8.2 Underpinning Concepts

In developing the decision-making process that will be described later in this chapter certain ideas have been influential. In particular, Kuczewski's communitarian casuistry[5] addresses some of the weaknesses identified in the previous chapter in Jonsen's approach to individual decisions.[6] Dworkin's 'prudent insurance' concept suggests ways to address macro resource allocation problems[7] although a greater ethical input will be needed than he suggests. The balancing and inquisitorial methodology adopted by some judges recently is important when the non-treatment decision involves a patient with impaired autonomy. The recommendations O'Quigley makes regarding ways to enhance autonomy within the legal decision making process, which I have already argued can be successfully adopted within the healthcare setting, have great value.[8] Finally, for those who anticipate long-term or permanent loss of capacity, the judiciary's acceptance of the validity of clear advance directives is particularly significant as are the recommendations in *Making Decisions*.[9]

8.2.1 Autonomy

Doctors have to act within a legal framework grounded in historical tradition and precedent. The traditional separation of medicine from law no longer exists as medical decisions are scrutinised by the courts. Medical negligence rose out of the belief that certain standards are required and, as shown earlier, standards are no longer solely medically determined.[10] Just because a doctor is proposing to act in the same way other doctors would act this conduct will not necessarily be accepted as proper or lawful by the courts. Medical ethics is no longer a matter for clinicians alone. Surgery, and pharmacology, have become things people 'volunteer' for

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[2]Klein R. Dimensions of rationing: who should do what next? *BMJ* 1993;**307**:309-311 at p310.
[3]Ibid, at p311.
[4]Kuczewski, op cit n1 at pp1-2.
[5]Ibid.
[6]Jonsen AR, Siegler M, Winslade WJ. *Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine*. 4th Edn. 1998 McGraw Hill, New York.
[7]Dworkin R. *Sovereign Virtue: The Theory and Practice of Equality*. 2000 Harvard University Press, London, in particular, at pp 307-319.
[8]O'Quigley, A. *Listening to Children's Views: The Findings and Recommendations of Recent Research*. 2000 The Joseph Rowntree Foundation, York.
[9]Lord Chancellor's Department. *Making Decisions* Cm4465 1999 The Stationery Office, London.
[10]See, for example, *Bolitho v City and Hackney HA* [1998] AC 232 and discussion earlier in this thesis.

rather than simply have as a desperate attempt to save life. Autonomy has become increasingly important as consent to treatment has developed into a medico-legal doctrine. Its value is well recognised by patients, doctors, judges and ethicists. Respect for autonomy requires that competent patients are involved in their treatment decisions, particularly when the consequence of withholding or withdrawing treatment is death. However, the empirical evidence obtained for this thesis suggests that it is over-optimistic to state that the medical profession accepts the concept of informed consent as 'a *fait accompli*'.[11] In order to make free, autonomous decisions patients need information in an understandable format and adequate time to assimilate it.[12] Expressing autonomous choice can be difficult but it should be encouraged despite the over-optimism of viewing man as 'eminently educable and capable of self-knowledge'.[13] The 'prevalence of cognitive, visual, auditory and language deficits'[14] which impair comprehension can be addressed by encouraging treatment 'try-outs'. It would be important to recognise that consent would only be valid for the limited period of the 'try-out'. If fresh consent is not obtained, treatment should be stopped. Some doctors may be reluctant to accept this, particularly with experimental treatment, where their reputations depend on the results.[15] Problematically, this thesis found anecdotal evidence that patients, once persuaded to 'try' treatment like dialysis, simply continue with it rather than positively affirming that this is what they wish. Consequently, pressure on resources increases.

When autonomy is undermined, or threatened, conflicts can occur. Doctors need to improve their communication skills, particularly when dealing with children or patients under a disability so as to enhance their ability to act autonomously. As Teff notes, '(o)ffering patients dialogue has more therapeutic value than offering them consent forms'.[16] The O'Quigley recommendations are valuable in enhancing autonomy.[17] Medical advances mean that the barrier between life and death has become blurred and living death is possible. Decision-making then becomes particularly problematic partly because the legal restraints of murder and manslaughter offences are no longer seen as appropriate in setting the boundaries of acceptable conduct in the medical domain and partly because the ability of previously competent patients to have their non-treatment preferences met after loss of capacity has been poorly supported. Although many senior lawyers and medical ethicists believe the courts are an inappropriate forum for medical decision-making[18] their role in conflict resolution and determining the lawfulness of actions is necessary. The courts have to engage with issues that were not previously their domain and, consequently, frequently defer to medical opinions of best interests when patients are unable to act autonomously. The use of advance directives should be encouraged and the legislature should facilitate national equality by giving all citizens the right to appoint proxy decision-makers. Good democracy and human rights demand this. Yet, for proxy decision-making to work well it must be recognised that proxies, like parents of minor children, will require 'hospital and community-based support designed to meet their informational and emotional needs and, most of all, to facilitate their expanded role in

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[11]Mason JK, McCall Smith, Laurie GT. *Law and Medical Ethics* 5th Edn. 1999 Butterworths, London at p288.
[12]Olde Rikkert MGM et al. Experienced consent in geriatrics research: a new method to optimize the capacity to consent in frail elderly subjects. *J.Med.Ethics* 1997;**23**:271-6 at p271.
[13]Jinnett-Sack, Autonomy in the company of others in Grubb A. *Choices and decisions in health care.* 1993 John Wiley & Sons, Chichester pp97-136 at p101.
[14]Olde Rikkert, op cit n12 at p271.
[15]An example of a surgical 'try-out' could be the grafting of a hand onto a patient. This is experimental treatment, and now, the first patient to be treated this way wishes the hand to be removed: Whittell G. 'Remove my hand' *The Times* 20 October 2000. This was eventually carried out: Nathan A, Chohan N. Doctors amputate first transplanted human hand. *The Sunday Times* 4 February 2001.
[16]Teff H. *Reasonable Care: Legal Perspectives on the Doctor-Patient Relationship.* 1994 Clarendon Press, Oxford at p238.
[17]O'Quigley, op cit n8 at ppvi-vii.
[18]See, for instance, the approval given to the views of Dr Grant Gillet by the Attorney General in *Auckland AHB v Attorney-General* [1993] NZLR 235 at p 241.

the decision-making process'.[19]

However, ethics must not lapse into 'the safeguarding of mere personal preferences'.[20] It is necessary to have a concept of the 'common good' in order to prevent this.[21] Supporting autonomy cannot mean fixing the boundaries between persons in a way that denies the relevance of 'shared cultural inheritances'[22] or changes in society and medicine. Practical reason is needed in order to help individuals understand 'the personal, institutional, or societal narrative and help us determine when it is time for a new good to govern the particular situation'. The examination of the personal, institutional or social narrative and the balancing of different interests has become an increasingly important part of the judiciary's role when they are called upon to resolve disputes between patients, families, doctors and budget-holders. For example, the Court of Appeal decided in *Re A (Conjoined Twins)* that not only did Mary's sanctity of life not trump Jodie's right to live but the prohibition on necessity as a defence to murder was not absolute.[23] This can be interpreted as reason determining that it was time for 'a new good to govern that particular situation'.

8.2.2 Openness

8.2.2.1 Openness about Treatment Costs and Success Rates

There needs to be openness about treatment options, costs and how decisions are made. As Kuczewski highlights, there is a need for 'public legitimation of norms and social policies and for a distinction between an ethical action and the process by which one promulgates an action as ethical'.[24] Greater openness about the costs of treatment to society will help enable ways to determine how societal interests should be balanced against individual need. However, the 'rules' by which non-treatment decisions are made by governments, budget-holders and doctors are characterised by a lack of openness which, as the public, often influenced by the media, becomes more questioning and demanding, has led to an erosion of trust. Consequently, the legitimacy of rules and guidelines is questionable.[25] Democracy is weakened.

The success rates of different centres and different practitioners should be openly available and in a form that allows valid comparisons to be made.[26] Good science requires openness and honesty about results. Patients should have the option of knowing as much or as little as they want about the different treatment options (NHS, private, foreign, experimental), success rates and prognoses. If this information is incomplete, and much medical knowledge is uncertain, this should be admitted. The lack of knowledge should not be interpreted as

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[19]Barber PA, Marquis JG and Rutherford Turnbull III H. 'Parental Perspectives on Treatment-Nontreatment Decisions involving Newborns with Spina Bifida.' In Caplan AL, Blank RH, Merrick CJ (Eds). *Compelled Compassion.* 1992 Humana Press, Totowa, New Jersey pp123-153 at p150.

[20]Kuczewski, op cit n1 at p2.

[21]Ibid.

[22]Ibid, at p109.

[23]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.

[24]Kuczewski, op cit n1 at p111.

[25]Ibid.

[26]For instance, *The Sunday Times* recently published a comparison of hospitals. Quoting capitation rates for the number of nurses or doctors per hundred patients is meaningless if a substantial number of these are part-time employees. Similarly, mortality indexes reflect only one type of outcome. Outpatient appointment times reflect access. Equality of outcome is not necessarily the same as equality of access (see discussion earlier in this thesis) so a hospital can achieve well in one category but poorly in the other (see, for instance, University College London Hospitals which did well on the mortality index but poorly on outpatients appointments and West Middlesex University Hospital which did well on outpatients appointments despite having substantially fewer doctors but scored worse on mortality). The failure to recognise and address these weaknesses makes interpretation of such tables difficult and possibly exacerbates public anxieties. Jarman, Sir Brian. *The Good Hospital Guide. Parts 1 and 2. The Sunday Times* 14 January 2001 and 21 January 2001. Available on www.sunday-times.co.uk/hospitalguide Accessed 14 January 2001.

a fault, either of medicine or the individual practitioner, since this could encourage doctors to cover up their deficiencies. However, identified weaknesses in individual knowledge that can be addressed, should be addressed, or the patient referred to someone with greater expertise in the patient's condition. An important part of medical expertise is the interpretation of clinical information and diagnosis, not necessarily healing. Doctors should be encouraged to separate their healing role from their diagnosing and informing role. At present, if they cannot cure, either because the condition is incurable, or because the resources are not available, they may be less open about diagnosis and prognosis thereby undermining the ability of patients to make autonomous choices. Greater openness will enable autonomous patients to make informed choices and will, likewise, help others who have to decide for the incompetent patient. Openness can help guard against value judgments based on third party estimations of patient quality of life being made. It can prevent discriminatory practices occurring. If words like 'futility' are used, there should be openness about the meaning to avoid distorting the decision-making process. There should be openness about what treatments do physiologically for patients. For example, in cases where the kidneys have failed, providing artificial nutrition shortens the dying process by allowing toxins to accumulate. Hiding this fact is dishonest and prevents debate as to whether this is acceptable. There needs to be openness about the fact that those who are involved in delivering care take into account different factors when withholding or withdrawing treatment. Pretending such differences do not, or should not, exist means the decision-making process will continue to be flawed as relevant reasons for the decision will be hidden to avoid censure. There needs to be openness about the way doctors practise, particularly when a palliative care model of treatment has been adopted.[27] It should be openly admitted that non-treatment decisions create great anxiety at times.[28] Doctors are not immune from the emotional drain that the threat of litigation, their possible criminal liability and their own desire not to fail their patients creates. This seems to be under-recognised because it is possibly seen as a weakness. Team-work and a culture of openness can help reduce anxiety.

8.2.2.2 Openness about Expertise

There needs to be openness about what the NHS can achieve and where its expertise lies. Its role has still never been clearly identified. In theory, it could be seen as to diagnose and treat all patients in a timely and equitable manner but it seems clear that this is beyond its resources. Therefore, rationing techniques, including a lack of openness about options, are used. Primary care concentrates on keeping patients out of hospital but this is not the full solution. Some patients will need hospital care. Medical advances mean that the ability of GPs to accurately diagnose illness has been weakened and it is increasingly necessary to refer patients to specialists. Consequently, some patients are not diagnosed in time for treatment to be useful or curative. Other patients get their diagnosis but do not necessarily receive the most appropriate treatment for their condition because of economic constraints. Not all of these patients are informed that better alternatives are available. Some receive this information but are told that the only way to potentially access the better treatment is to enter a research trial. Some patients are told of the economic or waiting time barriers to them receiving treatment and are able to access treatment privately or lobby health authorities or anyone they perceive has having a responsibility for resource allocation decisions. Equality can be enhanced if the NHS acknowledges that it cannot deliver timely diagnosis and treatment to all patients. Delays in diagnosis lead to inappropriate withholding of treatment. Concentrating on speedy diagnosis coupled with a commitment to openness about

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[27]Corner J. More openness needed in palliative care. *BMJ* 1997;**315**:1242.
[28]Door Goold S, Williams B, Arnold RM. Conflicts Regarding Decisions to Limit Treatment. *JAMA* 2000;**283**,7:909-914.

treatment availability and options will reduce unnecessary deaths whilst patients are awaiting referral to specialists for diagnosis. Government initiatives such as medical audit, more GPs, NHS Direct, drop-in clinics and breast cancer referrals show a commitment towards delivering speedy, and accurate, diagnosis. This should be enhanced. The NHS is ideally situated to deliver diagnosis even if it cannot always deliver treatment. Being open about what it can deliver and engaging in a process of identifying how individual need is to be balanced against societal interests will be the first step towards ensuring the NHS can survive as a universally accessible healthcare institution. Informed patients, armed with their diagnosis and a schedule of the different treatment options, statistical outcomes, costs and providers, would then be able to make decisions about whether to wait for their local NHS hospital to provide treatment or go elsewhere. Computer technology and medical audit make this a real possibility.

The role of doctors as 'expert in medical science'[29] must be reflected by any decision-making model. However, this does not mean that only medical science is decisive. If too casuistic an approach is taken, 'facts' can dominate the decision-making process due to a lack of 'clearly delineated principles or values to be employed'.[30] The uniqueness of each case must be maintained so patients are seen as individuals not as 'another case similar to one earlier'.[31] It is also important to recognise that facts and values cannot always be separated.[32] Whilst science, medicine and law might aspire to neutrality, their actors are only human as are their critics. Ascribing someone to a particular role means automatically invoking the criteria by which that person will be evaluated.[33] Therefore, a 'good' doctor is one who makes decisions in accordance with his peers but his peers might also act in a discriminatory or paternalistic manner. Because medicine is not solely science but also ethics, conflicts arise between facts and values leaving doctors subjected, at times, to 'a tyranny of universal principles' such as autonomy, beneficence and justice.[34] Many doctors lack expertise in law and ethics. As Campbell warns, '(c)onfusion about the ethics (or legality) of withholding and withdrawing treatment may...influence decision making in a subtle, but potentially dangerous way.'[35] Doctors can become too involved with the patient or the family and too concerned about appearing in control. Training can help address this but it is inappropriate to expect mastery in another's speciality so the input of others should be welcomed rather than excluded. The prejudice expressed towards other inputs that this thesis has found is highly regrettable since the expertise of others with greater understanding of ethical, and sometimes legal issues, is important in helping doctors to make decisions and assisting in complex cases.

The expertise of judges lies in law, balancing different views, logical, dispassionate, rationalising argument and demarcating legal boundaries but they lack expertise in ethical analysis. Consequently, some patients under disabilities have lacked sufficient protection of their interests.[36] The English judiciary are gradually becoming more proactive and recognising that just because a medical team holds that a certain action is appropriate, necessary, or the only course open to them, this is not always true. Therefore, judges are requiring more openness in the way doctors inform them about treatment options.[37] However, although a new Court of

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[29]Kuczewski, op cit n1 at p13.
[30]Ibid, at p113.
[31]The 'Blue Peter Model' of reasoning - see Chapter 5.
[32]Kuczewski, op cit n1 at p11.
[33]Ibid, at p10. See also, pp11-12.
[34]Ibid, at p100.
[35]Campbell AGM. 'Baby Doe and Forgoing Life-Sustaining Treatment.' In Caplan AL, Blank RH, Merrick CJ (Eds). *Compelled Compassion.* 1992 Humana Press, Totowa, New Jersey pp207-236 at p225.
[36]For instance, *In Re Y (Mental Patient: Bone Marrow Donation)* [1997] 2 WLR 556.
[37]For instance, see *R v St George's Healthcare NHS Trust ex parte S* [1998] 2 FLR 728; *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1 and discussion earlier in this thesis.

Protection is proposed[38], it would be better to acknowledge the limits of judicial expertise. As Kuczewski argues, '(t)he solutions of a law court are not always the answer or the proper authority...so the ultimate nature of the decision-maker is something that must be worked out for each range of cases'.[39] At present, decision-making moves from the bedside, possibly via a case conference, to the courts. That cannot be helpful. Too often the referral is because doctors are seeking legal security for themselves rather than trying to discover what is ethically right for the patient.[40] It would be better to have in-house ethics committees which could advise on individual cases but would have the ability to recognise when the issues to be resolved were beyond their remit or expertise. There should then be a tribunal system modelled on the successful ones that already act as an intermediary forum in the case of employment and welfare disputes. This could have inputs from people with appropriate expertise whose opinions are weighted equally.

8.2.2.3 Openness in the Decision-Making Process

However, simply accepting the need for openness is insufficient. The decision-making process needs a system that effectively builds openness into its structure rather than merely accepting it as a value to aspire towards. The process must identify who to ask, what to ask and how to ask. Since it is natural that some will be better at 'practical reasoning' than others it is important to be able to identify 'what goes into good practical reasoning, ...recognise when someone is doing it well, and be able to find ways of training people to improve this capacity'.[41] It must also be accepted that 'a finished product based on a theory of the nature of ultimate reality' can never be achieved.[42] Instead, the system that will be proposed can only be one small building block in the process of developing medical decision-making prowess.

8.2.3 Distributive Justice

Liberalism, according to Kuczewski, takes a 'posture of neutrality' which 'treats all choices as equivalent in the public domain and accords equal rights and opportunity' but, in so doing, 'rules out any attempt by government to aid or abet a notion of the common good'.[43] In reality, when macro resource allocation decisions are made, decisions are underpinned by notions of the common good and 'individual rights' turn out to be 'mere fictions' because individuals belong to families and wider communities.[44] It is impossible to conclude from this limited piece of research exactly how the balancing of individual and societal needs is best achieved. More research in this area is needed and it is suggested that this is a matter for government to facilitate. However, the research must be robustly constructed unlike the recent survey that underpinned the NHS Plan[45] since 'if the methodology used is predicated on an inequitable epistemology, which disenfranchises or is insensitive to the particular needs of certain groups, then any resulting...analysis will necessarily be inequitable'.[46] To that end, it would be more appropriate for such research to be conducted in a completely independent manner with guarantees that its findings will not be suppressed as occurred with the Black

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[38]Lord Chancellor's Department, op cit n9. See discussion in the previous chapter.
[39]Kuczewski, op cit n1 at p119.
[40]Nys H. Physician Involvement in a Patient's Death: A Continental European Perspective. *Medical Law Review* 1999;7,2:208-246 at p246.
[41]Ibid, at p12.
[42]Ibid, at p17.
[43]Ibid, at p103.
[44]Ibid, at p105.
[45]Department of Health. *The NHS Plan: A plan for investment, a plan for reform.* Cm4818-1 2000 The Stationery Office, London. Available on www.nhs.uk/nhsplan accessed 7 August 2000.
[46]Mannion R, Small N. Postmodern Health Economics. *Health Care Analysis* 1999;7:255-272 at p265.

Report.[47]

In balancing the demands/needs of the individual against the wider needs of society, it is necessary to identify what 'society' means. It could mean local community such as the communities for which PCGs will be identifying healthcare options and priorities. It could mean national community or cultural/ethnic community. Veatch describes how changes to organ allocation processes to prioritise need on a national scale have been resisted due to a belief that local community, a sort of extended family, should be looked after first and foremost.[48] National inequalities will continue under the PCGs. A proper decision needs to be made as to whether equality of outcome or equality of opportunity is the goal of state-funded healthcare. This should not be a purely medical or purely political decision since Veatch identifies that physicians are prepared to sacrifice some equity in favour of maximising efficiency whereas non-physicians give higher priority to fairness.[49] If it is accepted that all those engaged in analysis of healthcare decision-making, whatever their discipline, are 'essentially engaged in mutual discovery of the good' each contribution can be given proper value.[50] Doctors have medical expertise; economists fiscal expertise; lawyers analytical expertise and ethicists philosophical expertise. Adopting a monopolistic approach to non-treatment decisions is unhelpful. Engaging in 'deliberative public dialogue on our moral and ethical problems' will help.[51]

The role of doctors as agents of rationing on the grounds of limited resources needs to be reduced. It is clear it is a source of anxiety and can lead to inequity. Some, like Vollman, believe it is right for doctors to 'consider the principle of justice, which prohibits wasting resources needed by others' since treatment decisions 'ought to include the needs of other members of the community...who may be denied medical help because of limited resources'.[52] Others, like Friend, suggest that the doctor and family are only required to act in the interests of the patient, 'without regard to other unknown insured people' since, '(a)bstract notions of distributive justice cannot supersede the rights of a named, identified patient'.[53] If Vollman's argument is taken to its logical conclusion, no doctor could realistically justify the expenditure of any large sum of money on any patient unless s/he could demonstrate a significantly probable certainty that the patient will recover. However, it seems obvious that both justice and good medicine require that treatment is discontinued when it really is clinically futile.[54] There is an urgent need for better data in order to enable outcomes to be predicted more accurately and it is appropriate to consider outcomes when making decisions but decisions of distributive justice cannot be for individual doctors to make alone.

8.2.4 Non-Discrimination

The predominantly utilitarian model of healthcare delivery is clearly problematic so a way to balance societal interests with respect for individuals is necessary. Regarding macro decision-making, 'neither the concept of

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[47]Black, Sir Douglas (Chair). *Report of the Working Group on Inequalities in Health.* 1979 HMSO, London.
[48]Veatch RM. A New Basis for Allocating Organs for Transplant. *Kennedy Institute of Ethics J.* 2000;**10**,1:75-80.
[49]Ibid, at p78.
[50]Kuczewski, op cit n1 at p101.
[51]Ibid, at p120.
[52]Vollman J. For Love or Money: Commentary. *Hastings Center Report* 1995; July-Aug pp22-23 at p23.
[53]Friend M. *Commentary. Hastings Center Report* 1995; July-Aug pp22-3 at p23. Harris has argued along the same lines: Harris J. Justice and Equal Opportunities in Health Care. *Bioethics* 1999;**17**,5:392-404, in particular see p404.
[54]Dickenson D. Can Medical Criteria Settle Priority-Setting Debates? The Need for Ethical Analysis. *Health Care Analysis* 1999;**7**:131-137 at p133.

equity nor that of need is of much help' so decisions are made according to 'political expediency'.[55] This, and the need to consider fiscal requirements and re-election prospects mean the NHS is subjected to pressures that affect not only the lives of those it is delivering care to and their families but also those it employs. Consequently, the NHS is in a demoralised and inefficient state. Emphasis on market forces and encouraging individual responsibility for healthcare has changed to individual responsibilities for adopting healthy lifestyles but discrimination is potentially set to increase as government support for genetic screening increases, abortion of disabled babies is encouraged, and the elderly are deemed 'unsalvageable'. National values take precedence over cultural ones to a certain extent. This is important in guarding against discriminatory practices such as withdrawing treatment earlier from infant girls but national values become distorted by a politicised healthcare framework.[56] People with the same condition should receive the same opportunity to benefit from treatment regardless of where they live if a truly national health service is to be achieved.[57] The public perception is that 'the NHS is failing to provide an equal standard of healthcare for all'.[58] Kuczewski argues for a balancing of individual and societal interests by adopting communitarian casuistry so that the 'deliberative activity of rich case-analysis' includes 'the kind of public consensus and method of promulgation that is necessary to legitimate authority'.[59] Stoll suggests establishing 'consensus on the treatment...appropriate to certain groups and stages of disease' with society approving the criteria used for deciding priorities in the face of limited resources.[60] However, whilst a more open debate about issues of distributive justice is needed in order to reduce arbitrariness in decision-making and variability in practice in different regions of the country this could result in agreements that discriminate against certain groups. For instance, it may be decided that '(i)n times of resource scarcity, *advanced age is a morally relevant way* of selectively limiting the use of life-sustaining technologies at the public policy level' although 'gender, race, ethnic background, intelligence level and religious beliefs of patients are not'.[61] Campbell's fears that seeking societal consensus as to how to limit healthcare could lead to anxiety amongst the elderly and vulnerable that they are to be considered burdens on society who are failing in some unspoken obligation to end their lives could be addressed by a statement of protections.[62] The value of all individuals within society needs to be recognised and the decision-making process needs to be not just non-discriminatory, but anti-discriminatory. The methodology adopted must not be one that 'disenfranchises or is insensitive to the particular needs of certain groups'.[63] Concerns regarding racial discrimination[64] within the NHS must be addressed.

One way to improve macro decision-making and address inequalities and discriminatory practices is to allow government to continue to take responsibility but with constructive, impartial and informed input from patients and healthcare professionals.[65] At present, NICE and CHI are coming on line but they are both firmly situated within the political process. Political expediency has overridden scientific rigour in the selection of treatments to evaluate. Both NICE and CHI are concentrating on clinical issues and/or financial issues to the exclusion

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[55]Klein R, Day P & Redmayne S. *Managing Scarcity: Priority Setting and Rationing in the National Health Service.* 1996 Oxford University Press, Oxford at p26.
[56]Subramanian KN, Paul VK. Care of Critically Ill Newborns in India. *J.Legal Med.* 1995; **16:**263-275. See discussion earlier in this thesis.
[57]Harris J. Justice and Equal Opportunities in Health Care. *Bioethics* 1999;**13**,5:392-404.
[58]British Medical Association. *Healthcare Funding Review.* 6 February 2001 BMA, London (web.bma.org.uk/public/polsreps.nsf accessed 15 February 2001) Chapter 2 'Public'.
[59]Kuczewski, op cit n1 at p118.
[60]Stoll BA (Ed) *Ethical Dilemmas in Cancer Care.* 1989 The Macmillan Press Ltd, Basingstoke at p21.
[61]Weir RF. *Abating Treatment with Critically Ill Patients: Ethical and Legal Limits to the Medical Prolongation of Life.* 1989 Oxford University Press, New York at p383. His emphasis.
[62]Campbell A, et al. *Medical Ethics* 2nd Edn. 1997 Oxford University Press, Oxford at p142.
[63]Mannion R, Small N. Postmodern Health Economics. *Health Care Analysis* 1999;7:255-272. at p265.
[64]Millar B. Race against time. *Health Service Journal* 18 March 1999 at pp9-10.
[65]Alexander M. Real democracy demands a willingness to listen to genuine local voices. *Health Service J.* 18 February 1999 at p19.

of ethical issues. Whilst the framework for deciding questions of funding is really a separate issue from examining the withholding and withdrawing of medical treatment from individual patients, non-discrimination requires that account is taken of ethical values not just finances.

A better way to improve macro decision-making would be to separate healthcare funding from the process of identifying what treatments should be delivered through the NHS and which should be withheld. This could be achieved by having an independent body which has the role of establishing what the healthcare priorities should be and what treatments should be available on the NHS. Having a logical and independent appraisal of what treatments should be offered would enable government to identify what resources are needed in order to deliver timely and effective treatment. The BMA hints at such a body in its review of healthcare funding so it should command support from doctors although they over-emphasise medical and cost-effectiveness aspects of defining 'need' at the expense of ethical factors.[66] Unlike the Oregon model[67], which over-emphasised the importance of public opinion, the strategic body would need to have expert medical, legal, ethical and financial input. It is clear that there are some treatments which none would consider appropriate to withhold on financial grounds (eg appendectomy). Equally, a point which Dworkin fails to recognise sufficiently in his over-reliance upon medical effectiveness, there are some treatments which none would consider acceptable to provide on ethical grounds (eg female circumcision). Some of the treatments withheld may be available privately whereas others, on ethical grounds, may need to be prohibited by law to prevent human rights abuses. It may also be appropriate to legislate that certain conditions (eg smallpox) must be treated as a matter of public health and safety and individual refusal of treatment is not an option. In addition to examining the medical effectiveness of different treatments for different conditions, the ethical and financial limits of what it is acceptable for the state to fund or not fund could be identified by the strategic body. Having such a body would answer Butler's criticism that '(n)ot only is the search for a morally correct solution to the problem of rationing a chimera, so too must be the belief that a consensual solution, were it ever to be found, would be technically feasible'.[68] The strategic body would be able to produce greater equity within the system as called for by Bell.[69] However, it is recognised that the recommendations of the strategic body may result in pressure being brought to bear upon government to increase the funding given to the NHS but that should be a small price to pay for achieving a nationally equitable healthcare service which delivers care in a non-discriminatory and anti-discriminatory fashion.[70] Such a healthcare service could then be a beacon for the world to follow.

8.3 A New Approach to Macro Resource Allocation Decisions

8.3.1 The Work of the Strategic Body

Once an independent strategic body has been set up the process of identifying which treatments should be available on the NHS and which withheld can begin. Given the impracticality of immediately evaluating every

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[66]British Medical Association, op cit n58 Chapter 2 'Public' p3.
[67]Discussed earlier in this thesis.
[68]Butler J. *The Ethics of Health Care Rationing: Principles and Practices.* 1999 Cassell, London at p233.
[69]Bell A. It's not fair: issues of equity in NHS health care. *Br.J.Health Care Management* 2000;**6**,12:580-581.
[70]In fact, the BMA suggest that politicians may be over-sensitive because 'increased spending on public services need not involve great political sacrifices..and could...be a sign of efficient management of public finances rather than the opposite': British Medical Association, op cit n58 Chapter 4 'The Affordability Gap' p1.

possible treatment option, an initial identification of those conditions most agree should be treated and those most agree should not be treated on the NHS should be made. To a certain extent, that will be based on commonsense as Dworkin recognises.[71] Once these have been decided, the clinical and cost effectiveness of the different treatment options can be assessed. This will allow fine tuning of the list to begin. The strategic body could identify treatments which will always be available on the NHS, for instance, appendectomies, antenatal care and delivery, childhood vaccinations and treatment for broken limbs. If the strategic body decides that treatment should be available then the funds for this should be made available by the state. These treatments and the funds for them could be ringfenced to ensure that they will be available to all in a timely fashion. Even sufficient bedlinen could be a ringfenced cost. Unlike hypothecated taxes which are popular with the public but not with governments[72], ring-fencing of some of the NHS funding could command both public and government support. Doctors would be free to select from the list of available treatments freely, just as they do very much at present with many treatments and drugs.

In between the always give and never give treatments, there are 'grey areas' which need to be addressed by the strategic body.[73] Within the grey areas there will be some treatments which are a matter of resources and others which are a matter of ethics. Tattoo removal could be considered a matter of resources since tattoos are not life-threatening and the person was a volunteer in the first place. Gender reassignment or separation of conjoined twins are ethical issues. Currently, debate is dominated by clinical opinion with ethical input often being of an extremist nature.[74] The order in which full clinical and cost-effectiveness evaluations are conducted of treatments falling into the 'grey' area where there is disagreement over whether the NHS should provide them could be determined by a wider public dialogue. This is because the decision-making process needs to move beyond the assertion of Auld LJ that, '(i)n establishing priorities - comparing the respective needs of patients suffering from different illnesses and determining the respective strengths of their claims to treatment - it is vital for an authority: (1) to accurately assess the nature and seriousness of each type of illness; (2) to determine the effectiveness of various forms of treatment for it; and (3) to give proper effect to that assessment and that determination in the formulation and individual application of its policy.'[75] In order to protect 'the legitimate claims of the patient on the community' it is necessary to adopt 'a notion of the duties of the community to the person'.[76] Rights are not just for safeguarding private individual interests but also have an 'instrumental aspect regarding the life of the community'.[77] Communal discussions can assist in developing a jurisprudence that balances individual interests with societal interests but government must recognise that 'some issues are better handled...through promulgation by policymakers and indirect assent by the citizenry'.[78] The flawed consultation exercise preceding the NHS Plan demonstrates political expediency at the expense of research robustness.[79] However, handled well, communal deliberation 'permits the possibility of shaping the social world and engenders responsibility for helping create the future'.[80] Stoll's call for societal approval of

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[71]Dworkin, op cit n7 at pp313-314.
[72]British Medical Association, op cit n58, Chapter 4 'The Affordability Gap' at p2.
[73]Ibid, at p316.
[74]Catholic papers claimed the courts were 'legalising involuntary euthanasia' in the case of *Re H (A Patient)* [1998] 2 FLR 36: Caldwell S. Euthanasia Fear Grows - Feeding may be denied crash victim. *The Universe* 24 November 1996.
[75]*R v North West Lancashire HA, ex parte A, D & G* [2000] WLR 977 at pp991-992.
[76]Kuczewski, op cit n1, at p107.
[77]Ibid, at p109.
[78]Ibid, at p112.
[79]See discussion earlier in this thesis.
[80]Kuczewski, op cit n1 at p108.

rationing criteria could be answered.[81] A 'public dialogue in which we enter as equals'[82] seems appropriate for deciding how to balance the interests of groups of individuals against societal interests once the larger question of what percentage of revenue should be allocated to the NHS over and above that which is needed to fund those treatments identified as 'must treats'. So, for instance, the question of whether infertility treatment represents a proper use of NHS funds and should be prioritised over other 'desirable' treatments could be made by the strategic body. That way, because it would be completely separate from government, unlike NICE, its decisions could gain greater societal acceptance.

Once the strategic body has identified the treatments that all agree should be given in a timely manner, a costing exercise can be done. It is submitted that the government should ensure that sufficient funds are available so that the 'must-treats' can be treated in a timely, effective and nationally equitable manner. Once this has been done, regional inequalities can be tackled effectively. At present, the government aim is to reduce regional inequality in certain key treatment areas without identifying how to tackle inequalities in 'grey' areas where some hospitals offer more advanced diagnostic or screening tests, treatments such as IVF or laser treatment, novel techniques such as artificial hearts or a particular expertise in certain types of surgery. At present, there is merely speculation that because less is spent compared with equivalent countries like France and Germany the NHS is underfunded. However, it is submitted that the percentage of GDP that is put into health in the U.K. may really be insufficient to meet adequately the needs of its citizens. An independent, rigorously conducted appraisal would yield the information necessary. If the strategic body says these conditions must be treated and these are the best treatments, in our opinion, taking into account ethics, medical effectiveness etc then the government is going to have to face hard questions if delivering those treatments to all citizens in a timely manner is going to exceed what it wants to put into healthcare. For example, it may be that the 'must treats' already swallow up 90% of the present amount allocated to health and the NHS is trying to deliver some of the 'desirable but not strictly necessary' treatments as well. To deliver those 'desirables' in a timely and equitable manner would perhaps cost 20% of the current budget but there is only 10% of the budget left so some people don't get timely 'must treat' treatments because other specialties in their area are swallowing up moneys that should be going their way. Government must meet this challenge because otherwise, as medicine advances, the desirables will start eating away further at the 'must treats' budget and then ways to restrict who will get the 'must treats' such as age-limits will become increasingly prevalent at a time when people are actually able to live longer and more healthily than before and these restrictions are likely to become increasingly arbitrary or discriminatory. Ultimately, the state should fund the NHS sufficiently so that all hospitals and specialties achieve the level of care of the better ones and all patients receive the same opportunities. However, if the government of the day refused to fund in full the recommendations of the strategic body, the body would have to set priorities in a medically robust, open, fair and equitable way that recognises the value of all citizens. At the same time, government under-funding could be challenged through the democratic process.

New or experimental therapies and treatments that are not strictly addressing a matter of ill-health would also fall into Dworkin's 'grey area'. What is needed is 'rigorous evaluation of therapies, a technique that modern medicine is only now learning to perform in theory and has far to go in applying to practice'.[83] Jonsen

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[81]Stoll BA (Ed) *Ethical Dilemmas in Cancer Care*. 1989 The Macmillan Press Ltd, Basingstoke at pp24-26..
[82]Kuczewski, op cit n1 at p112.
[83]Jonsen et al, op cit n6 at p56

approves Moore's sentiment that '(t)here must be some likelihood of success before the desperate remedy becomes more than a desperate search for an opportunity to try a new procedure awaiting trial'.[84] The treatment proposed for Child B was experimental and what was eventually tried had never been tried before.[85] An appropriate safeguard would be to have a code of practice that sets out ethical, legal and scientific standards that should be met. This could set out whether approval should be sought prior to the new treatment being given and who should give such approval. It could delineate the evaluations a doctor should make where the situation is an emergency. These need not be onerous and would probably reflect the analysis that the best doctors automatically make in such situations already. The doctor who can demonstrate scientific and peer support for an experimental procedure will have little to fear but the maverick would be partly controlled.[86] The decision as to whether the state will fund experimental treatments could be taken by the strategic body who could delineate any special requirements such as whether funding approval should be sought.

There could be a separate, nationally or locally administered fund for purchasing treatment in the private sector or funding experimental treatment. Treatments such as IVF and tattoo removal that will only rarely be given could be subject to a special demand fund the size of which would be determined by government and subject to other demands on its revenues. There could be competition for these treatments, or for funds, by patients or hospitals. Whilst this might be unpopular initially with some doctors who wish to expand their expertise and enhance their personal reputations, anomalies such as IVF treatment being provided for a lucky few whilst the funds for an MRI scanner have to be raised by local endeavour should disappear as the equipment and facilities for diagnosis are prioritised. The BMA, itself, implies support for this proposal since it believes that encouraging 'a private sector market for those (treatments) which do not meet the criteria for public funding, and research funding to develop cost-effective solutions in the long term, will help to maintain incentives for further innovation'.[87]

The investigations of the strategic body may yield information that is hard to handle. For instance, some non-treatment options may be more costly for society whereas some may save society money. More costly options include autologous blood transfusions and patients remaining in hospital because they refuse surgical treatments like amputation. Society possibly needs to consider whether patients whose choice is more costly to society than what the doctor recommends should be asked to fund the difference or whether society is prepared to accept this extra cost. As with education, it might be decided that the state should provide a basic, 'non-denominational' service for all but additional costs that arise due to religious preferences will have to be met by the family or their religious community. Perhaps the extra costs balance out because some patients will die because of their refusal and some patients will die because they do have treatment but, at present, this is unknown. If respecting autonomy is more costly to society, perhaps the rationality or plausibility of the patient's decision would then be determinative of whether society will cover the extra costs. The question whether there is an ethical obligation on society to provide treatment at extra costs to satisfy someone's personal preferences, whether inspired by religious/cultural values or not, needs to be openly addressed by the strategic body with appropriate inputs. In order to protect the 'genuine interests of health care service users' the NHS needs to safeguard key aspects including 'the provision of advice, information, and services which

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[84]Ibid, at p51.
[85]Ham C, Pickard S. *Tragic Choices in Health Care:* The case of Child B. 1998 Kings Fund, London at p30.
[86]It is recognised that the determined doctor who wishes to act outside legal and ethical parameters will always be able to find a way to do so but measures such as regular appraisal and audit can eventually detect Shipman-type mavericks.
[87]British Medical Association, op cit n58 Chapter 4 'The Affordability Gap' at p2.

are aimed at real human needs and are in accordance with acceptable standards of efficiency and professional excellence'.[88] This safeguarding can be strengthened by accepting a concept of rights as 'procedural guarantees'.[89] There should be a key statement that an overriding principle is that in establishing the framework, discrimination on the grounds of age, sex, culture, religion, ethnic background or disability is totally unacceptable. As Harris affirms, '(e)qual opportunities recognise the existential or intrinsic value of people'.[90]

Regarding patients who refuse recommended treatment, the strategic body may recommend that hospitalisation should not be provided without the patient accepting intervention. So, the patient who refuses medical treatment, but still requires nursing care, could be moved to a more appropriate centre although the option to change his/her mind and accept treatment should be made clear. In other words, the patient who refuses treatment will be treated just the same as the patient who no longer needs 24 hour medical care available. The strategic body would have to consider time-restricting certain treatments. Questions have to be addressed such as, if improvement is likely to be minimal, is continued funding of care justified? It may be appropriate for individual and societal interests to be balanced by deciding that the state will ask that artificial nutrition and hydration are withdrawn if a patient has remained in a vegetative state longer than some minimal period that should be decided with input from the public, medical experts, ethicists and lawyers. Whilst some suggest that patients in low awareness states should be classed as dead since this would 'eliminate the physicians' responsibilities to these patients' and '(d)ebates about appropriate care, rationing, and futility...would become irrelevant if these patients were defined as dead'[91] this is too far a step at present as recognised in *Re A (Conjoined Twins)*.[92] Not only would difficulties arise regarding threshold-setting but emotionally, it seems unlikely that families could accept this.

8.3.2 A New Model for Making Decisions at the National Level

The strategic body should ask...

1. What is the condition?
2. How serious is it?
   - Life-threatening but treatable - presumption in favour of treating to save life and preventing spread of disease
   - Life-threatening and incurable - presumption in favour of providing palliative care to ensure the best possible quality of life.
   - Reduces quality of life significantly - presumption in favour of treating where quality of life can be improved.
   - Reduces quality of life slightly - funds may be available once other, more serious conditions have been treated. This may be a condition that is not an appropriate one for public funds to be spent on.

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[88]Campbell AV, GillettG. 'Autonomy Revisited.' In Campbell AV, GillettG. *Ethical Issues in Defining Core Services. Discussion*, National Advisory Committee, Wellington, New Zealand pp 50-66 at p60.
[89]Kuczewski, op cit n1 at p101.
[90]Harris J. Justice and Equal Opportunities in Health Care. *Bioethics* 1999;17,5:392-404 at p399.
[91]Payne K, et al. Physicians' Attitudes about the Care of Patients in the Persistent Vegetative State: A National Survey. *Ann.Int.Med.* 1996;125,2:105-110 at p108.
[92]*Re A (Conjoined Twins: Medical Treatment)* [2001] 1FLR 1.

3 Does the law require that the condition is treated regardless of patient consent because it is necessary for public health and safety?

- Treatment is legally required - funds should be ring-fenced to ensure the most ethically acceptable and medically effective treatment possible is given. The presumption that the legal requirement for the condition to be treated is based on a sound medical and ethical basis should be regularly reviewed.
- The law is silent - consider the ethical acceptability of treating the condition.

4 Is treatment of the condition ethically acceptable?

- Treatment of the condition is ethically required - presumption in favour of ensuring sufficient funds are available. Consider the ethical acceptability, the medical effectiveness and the cost effectiveness of different treatments for the condition.
- Treatment of the condition is ethically acceptable - consider the ethical acceptability, medical effectiveness and cost effectiveness of different treatments for the condition.
- Non-treatment of the condition is ethically acceptable but may be desired by individual patients - consider ethical acceptability, medical effectiveness, lawfulness and cost-effectiveness of different treatment options.
- Treating this condition is ethically unacceptable - treatment will not be available and may possibly be a candidate for prohibition by the legislature.

5 What is the ethical acceptability of the different treatments for a specific condition?

- The treatment is ethically acceptable - consider medical effectiveness, lawfulness and cost-effectiveness.
- There may be some treatments where the ethical status is uncertain or possibly controversial. Further analysis will be necessary and guidelines should be issued by the strategic body for when it may be appropriate to discuss the treatment with an individual patient or refer the decision regarding an individual patient to an appropriate tribunal or ethics committee.
- The treatment is ethically unacceptable - this treatment will not be offered.

6 How clinically effective is each ethically acceptable treatment option?

- The treatment is highly effective - presumption in favour of making this available. Consider lawfulness and cost-effectiveness.
- The treatment achieves an acceptable level of effectiveness - consider lawfulness and cost-effectiveness.
- The treatment is of little efficacy - the less effective a treatment is, the less likely that it will be made available, unless more effective treatments are not available.

7 Is the treatment option lawful?

- The treatment option is lawful - this treatment can be provided subject to cost-effectiveness.
- The legal status is uncertain - further consultation is necessary and the ethical status and medical reasons for providing treatment should be considered more fully. If necessary, guidance should be issued to doctors for use with individual cases which will set out the procedure to follow in order to have the lawfulness of the option established.
- The treatment option is prohibited by law - it will not be offered by the NHS. Whether the current legal position is out of step with medical and ethical values should be clarified.

8 Is the treatment option cost-effective?

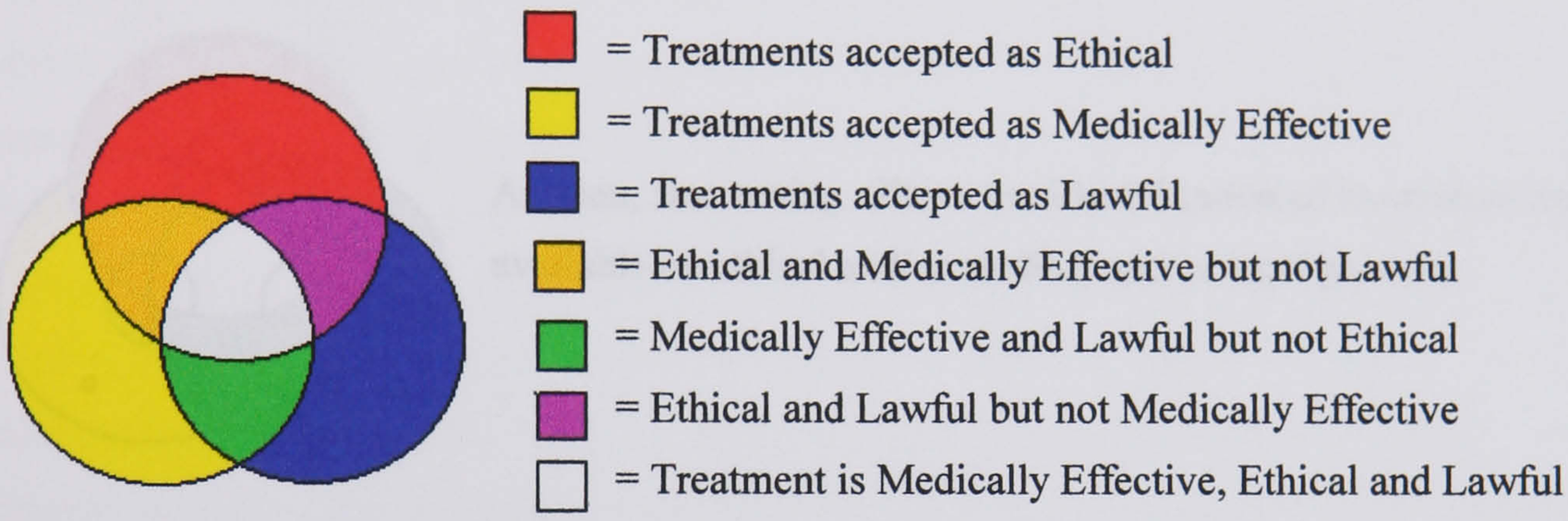
- Financially acceptable options should be offered by the NHS. Certain treatments for a condition could be identified as first-line options with more expensive options as second-line

unless individual characteristics of the patient indicate that first-line treatment should begin with the more expensive option. Guidelines should be issued to support good medical practice at the individual patient decision-making level.

- The treatment option is not ethically required and represents an inappropriate use of scarce public funds so it will not be available on the NHS.

The decision-making processes of the strategic body should be open to public scrutiny and the reasons for the decisions explained. Also, as Dworkin says, 'its results must be...open to revision on the basis of further evidence of public preference as well as medical technology and experience'.[93] The results must also be open to revision in light of emerging ethical and human rights insights.

8.3.3 A Diagrammatic Representation of How the Model Works



This model represents very simplistically whether particular treatments are ethically acceptable, medically effective and legally permissible. The strategic body will use its medical, ethical and legal expertise as filters to identify which treatments fall into which of the three main zones. Many treatments which are already being offered by the NHS will fall into all three zones and hence are placed in the central White zone thereby forming the first stage of a 'medical-social triage' in healthcare.[94] Some treatments will fall into two zones but not the central White zone. All the zones will be fluid and sometimes there may be uncertainty as to where different treatments belong. This 'greyness' will be for the strategic body to identify and work out how to address either by means of recommending further medical research, requesting that the government commissions an inquiry into the associated ethical and legal issues or issuing guidelines to assist in individual cases.

8.3.3.1 The White Zone Treatments

A State funded healthcare system should concentrate on delivering, to whatever extent is compatible with national priorities and budgets, treatments in the White zone since these are the ones where medical effectiveness, lawfulness and ethical acceptability are in concordance. It is accepted that it may not be possible to provide timely treatment to all citizens of every treatment that falls within the White zone but it is inappropriate for a state-funded system to provide treatments which are outside the White zone when it is

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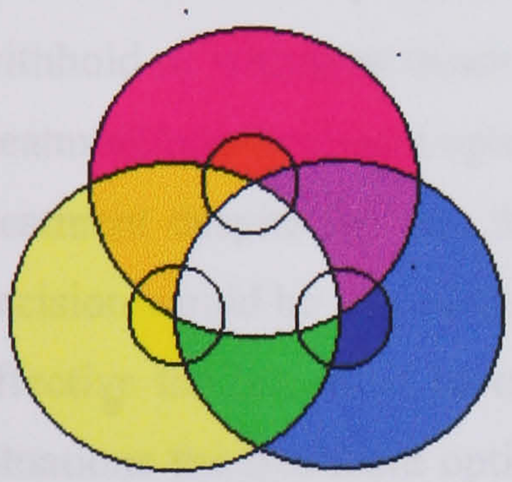
[93]Dworkin, op cit n7 at p318.

[94]I am indebted to Professor Carol Leppa, University of Washington, Seattle, for coining this phrase for me. We believe it is original.

having to limit White zone treatments on cost grounds. The treatments in the White zone should include palliative care for patients who cannot, or do not wish to, be treated. Once the initial zoning has been carried out, fine-tuning can begin. The expertise of the strategic body will enable it to begin to identify that within each of the three zones, there will be some conditions that it is ethically, medically or legally required that treatment is made available. These can be placed within circles at the centre of each of the three main zones. Where these circles overlap into the central White zone this indicates that the opportunity for treatment must be made available on the NHS - it is unacceptable to leave treating the condition a matter of individual finances (and/or personal choice in the case of conditions which are so threatening to public safety that treatment must be given regardless of personal wishes). In making its recommendations, the strategic body should give the highest priority to the 'must treats' and the funds for these should preferably be ring-fenced by government. Examples of 'must provide' treatments are effective pain relief in palliative care on ethical grounds and treatments for diseases, such as smallpox, that pose such a serious threat to public safety that legislation provides for treatment regardless of patient consent. An example of a 'condition' where there may eventually be a legal requirement for 'treatment' to be given regardless of patient consent, or the willingness of psychiatric units to provide treatment, is 'dangerously severe personality disorder'[95].



As seen, fine tuning allows the identification of treatments that must be made available on ethical and/or medical and/or legal grounds.

Then the process of prioritising the 'desirable' treatments for conditions that it may be appropriate for the state to offer to fund treatment for its citizens begins. The medical and cost effectiveness of different treatments within the White zone for the same condition should be examined. The Statement of Protections will be relevant in assisting how to set priorities between different White zone treatments for different conditions to prevent discrimination. However, some treatments may represent a disproportionately large part of the overall healthcare budget if they were to be provided completely freely so it may be appropriate for the strategic body to use its ethical, medical and legal expertise to draft guidelines which may help doctors identify which patients should be offered these treatments. Examples of such treatments which may need supporting guidelines, as NICE has recognised, could be Arocept for Alzheimer's or Relenza for influenza . The drafting of guidelines should not be left for the state to do because decisions could be dominated by costs and possibly by inappropriate considerations such as the worth of certain individuals to society. On the boundaries of the White zone are treatments which fall into either the Purple, Orange or Green zones. Medical advances and changes in society's views (possibly reflected in legislative changes) mean that all the zones are fluid. Treatments which presently fall into the White zone may become less effective compared with new drugs or operations and so fall out of the medical effectiveness zone and consequently, fall out of the White zone. Changes in societal attitudes towards medical advances or individual disability may mean that treatments seen as ethically acceptable are no longer seen as that. Conversely, medical advances and changes in ethical and legal opinion can mean that new treatments move into the White zone whereas, before, they were only in one of the bordering Purple, Orange or Green zones. The strategic body will need to continuously monitor the treatments

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[95]Secretary of State for Health. *Reforming the Mental Health Act* (Cm50161) December 2000. The Stationery Office, London.

it is recommending should be provided.

8.3.3.2 The Red Zone Treatments

Achieving consensus as to what constitutes ethical practice may be more problematic than identifying what is medically effective or lawful. What is seen as ethical may be either politically driven or in political dispute. Professional training as well as personal beliefs may influence attitudes. The question could be asked, whose ethic informs decision-making? By addressing these issues openly, it is submitted that a greater convergence between different ethical approaches could be achieved and the medical-social triage which the strategic body will be looking to achieve would command public acceptance. It is unlikely that many treatments would fall solely into the Red zone because ethical acceptability must be doubtful if the treatment is neither medically effective nor lawful. There may be ethically acceptable treatments which are of poor medical efficacy but, since English law tends to permit what has not been specifically prohibited the likelihood of an actual prohibition is remote. An example of where ethics could be out of step with medical practice and the law may be uncertain could be when artificial nutrition and hydration of a patient is in question. The medical treatment could, in the case of a severely brain-damaged patient, be of little efficacy but it would be ethically acceptable to either withhold or withdraw treatment or to continue treatment. If the law had to determine the lawfulness of the treatment/non-treatment options and decided that treatment was unlawful, it could be seen to be requiring non-treatment despite the fact that treatment could be seen as ethical. In such a situation, the non-treatment decision would be forced upon doctors and patients/families. Where treatment could be ethical and possibly effective the law must be cautious about insisting the treatment option is unlawful. In contrast, in some situations the treatment option might be non-treatment. Problems would arise where, for instance, even if treatment is of low efficacy but might possibly save life (hence could be ethically acceptable), non-treatment seemed unacceptable legally (either because of legislation or through the impact of the tort of negligence). Doctors could end up treating patients against their better judgment because they fear 'the judge over their shoulder'. At that point, treatment could be seen as becoming unethical depending upon the circumstances of the individual patient.

8.3.3.3 The Yellow Zone Treatments

Treatments that fall solely in the Yellow zone are ones that are medically effective but neither ethical nor lawful. An example could be carrying out a kidney transplant using a kidney that the patient had bought on the Internet. In such a case, the law has actively prohibited such transplants taking place in Britain because of the ethical unacceptability of trade in human organs. Another example, may eventually be the development of the ability to successfully clone human beings. As with the other zones, the boundaries between the Yellow zone and adjoining ones will be fluid. Ethical opinion and laws may change to meet changing circumstances. In the past, there has been a tendency for medical efficacy to dictate what was ethical and lawful. As new treatments are developed by doctors pushing out the boundaries of medical science, the strategic body will have to continually re-appraise the ethical and legal acceptability of the advances.

8.3.3.4 The Blue Zone Treatments

Treatments that fall solely in the Blue zone are legally acceptable but neither medically effective nor ethically acceptable. Treatments which fall solely in the Blue zone may represent out-dated practices and the strategic

body should investigate whether the law is out of step with ethics and should be modified or whether it is sufficient merely to provide guidance to doctors so that they avoid giving treatment that merely has its lawfulness to recommend it. An example of a Blue zone treatment could be the use of regression therapy with patients suffering from paranoid schizophrenia. The treatment is lawful but is of no medical efficacy for this particular condition and, in fact, could be positively harmful (hence, unethical). Of course, if a patient were to receive this treatment, and suffer harm, the doctor may be held negligent. In that case, it would then become apparent that the treatment was not a lawful option for that condition. The strategic body would need to monitor the appropriateness of different treatments for different conditions so that its recommendations were not out-dated.

8.3.3.5 The Purple Zone Treatments

It is a waste of scarce state resources to fund treatments which fall in the Purple zone since these represent poor value for money because they are not medically effective or only poorly effective. However, it may be appropriate, as part of the process of developing more effective treatments and/or cures/symptom-relievers/symptom-controllers, for the state to agree to fund some of these treatments under controlled conditions. For instance, some of the Purple zone treatments might fall into research trials and delivered under ethical and scientific protocols. Novel or experimental treatments, such as the treatment for which Jaymee Bowen's father sought to secure NHS funding, fall into the Purple zone. An example of a Purple zone treatment that is currently being provided on the NHS in some areas is in-vitro fertilisation treatment for infertility. It may be appropriate for guidelines to be developed, based on best research evidence to date, which will suggest when it may be appropriate for patients to receive these treatments. This could be part of the role of the strategic body. That way, treatments which may be of increasing medical effectiveness as greater knowledge and understanding about how and when they work can start to be recommended for provision on the NHS. For instance, guidelines could help target the use of beta interferon for multiple sclerosis towards those patients it could benefit.

8.3.3.6 The Orange Zone Treatments

Treatments which fall into the Orange zone represent examples where, for some reason, the law is out of step with what is held to be both medically effective treatment and ethically acceptable treatment. It cannot be seen as appropriate for a state-funded healthcare system to fund treatments which, if provided, are liable to result in the providers (and possibly the recipients) in facing criminal charges. This could represent a situation where medical advances and changes in philosophy have out-stripped the law or where legislators have been influenced by a vociferous, but not necessarily representative, group. An example of an Orange zone treatment could be abortion. Prior to the legalisation of abortion, it was considered ethically acceptable by many people and could be carried out in a medically effective way but most doctors were unwilling to carry out abortions. A second example could be euthanasia. There is a pro-euthanasia lobby which would like to see the law changed. Some doctors are prepared to extend the Doctrine of Double Effect to the boundaries of lawfulness. A lack of state-funded palliative care support means that euthanasia could become seen as ethically-required, not just, as at present, ethically acceptable to some people and in some forms. Consequently, the pressure for legislative change would increase. Another example is that of surrogacy where, admittedly, as with euthanasia, opinion is divided over whether it is an ethically acceptable remedy, so perhaps it does not belong in the Red (ethically acceptable) zone at all. The law has intervened to set out restrictions upon surrogacy. It can not be

seen as acceptable for the strategic body to recommend any treatment for provision on the NHS which it would be impossible to provide within the boundaries of the existing legislation. Opponents of legislative restrictions upon treatment that is generally accepted as ethically acceptable and medically effective will have to use the tools of democracy to bring about a change in the law. However, the same democratic tools are available for those who believe the law should restrict certain treatments and they also may campaign for changes. For example, the pro-life lobby believe that abortion laws should be changed. The strategic body should consider whether certain treatments are becoming available which could be of questionable lawfulness and should issue guidelines to assist doctors in making decisions and/or refer concerns to an investigative body which could report to parliament as has been done with regard to issues of human fertility.

8.3.3.7 The Green Zone Treatments

Treatments which fall into the Green zone are both medically effective and lawful but their ethical acceptability is doubtful. These treatments may be ones that have been carried out by doctors, behind closed doors for years and the law has not intervened because it was possibly unaware of what was happening. At some point, the legal system may be involved and have to carry out an examination of what is lawful. The over-reliance of the judiciary on medical opinion in the past has lead to situations where both the lawfulness and the ethical acceptability of the treatment in question has been dictated by medical practice rather than expert ethical opinion. An example of a Green zone treatment could be the use of hysterectomy as a method of controlling the fertility of people with learning disabilities. Although applications to the court for a declaration of lawfulness are required when the patient is an adult, no such application is currently required if the patient is under eighteen years and the doctor considers the operation 'therapeutic' so medical opinion and parental consent can result in what many consider to be unethical practices. Another area where the ethical acceptability of treatment may be in doubt is the use of plastic surgery to modify the typical facial features of children with Down's syndrome. Some of the treatments which fall into the Green zone may be ones where the law dictates that a certain condition exists and must be treated regardless of the consent of the patient, for instance, severe mental illness or smallpox. If treating a certain condition is legally required, but the treatment is ethically unacceptable, alternative treatments should be sought. If it is not possible to treat the condition except by using an unethical treatment strong representations should be made by the strategic body that parliament should reconsider the legislative compulsion and that research should be conducted to try to develop ethically acceptable treatments. Ethically-prohibited treatment should not be an option. In cases where there is a legal requirement to treat, the type of treatment that is most ethically acceptable to the patient, least invasive and least abusive of the patient's human rights should be used. The strategic body should issue guidance for use with individual patients. The strategic body needs to be alive to the potential for abuse of human rights in the name of medical efficacy and the burdens that some patients place on their families and/or society. It would not seem appropriate for the strategic body to recommend treatments for provision by the NHS that were of dubious ethical acceptability. Nor should it be a part of the remit of the strategic body to decide who presents a burden upon society nor how that burden should be relieved.

8.3.3.8 Treatments which Fall Outside the Zones

With some treatments it is impossible to know, without examination of individual cases, whether treatment is going to fall into any or all of the zones. For example, in the case of the conjoined twins, there was a certain amount of uncertainty about the results of the separation operation for the twin (Jodie) whom the doctors hoped

to save. There was a risk that she would die during the operation or within a few months of it. She would certainly need further operations but no one could state for certain how many, or what. No one was able to state for certain whether she would be able to walk, have bowel control, or have children. Therefore, it was not possible to say definitely that the separation represented medically effective treatment. Ethically, it was clear from the surrounding debate, that opinion was divided upon whether the separation should go ahead. The operation would cost the twin (Mary) her life and that raised issues about sanctity of live versus quality of life. In the long run, the burdens of treatment for Jodie might end up outweighing the benefits of treatment. Opinion was divided as to whether the parents should be allowed to refuse the separation. Not all doctors would have taken the same approach as the Manchester team. Legally, the position was uncertain and it fell to the civil courts to examine both the questions of the children's best interests and issues of criminal law. Consequently, the legal process dominated a highly sensitive ethical issue of medical treatment or non-treatment although it is accepted that the judges did their best to investigate both the ethical issues and the medical uncertainties. Added to the uncertainties of ethics, medicine and law, was the issue of costs. Obviously, costs were not determinative but they cannot be considered as irrelevant when rationing of treatment is a reality in a state-funded system nor should they been seen as irrelevant when carrying out treatment means that a commitment to continuing treatment and further operations is needed yet may not be forthcoming from the country of origin. If the case could have be considered by an independent tribunal consisting of equally weighted legal, medical and ethical opinion, a more satisfactory, though not necessarily different, decision could have been made. It could be seen as appropriate for the strategic body to issue guidelines to assist in making decisions for individual patients.

8.4 A New Approach to Decision-making for Individual Patients

8.4.1 Withholding or Withdrawing Treatment from Individual Patients

Where there is evidence of the patient's own beliefs or preferences, these should be relevant, though not decisive, factors since respect for persons demands that they receive due consideration. Whilst a patient-centred approach to scarce resources is important it cannot be appropriate for patients, or families, to restrict, for selfish reasons, the access of those who might benefit more from using the resource. Individual rights to life have to be balanced against the rights of others to life and not to have scarce societal resources wasted. 'Futility' is misused and inappropriate decisions are made based on 'quality of life assessments' rather than a premise that life is valuable. Obviously, the 'grading of human beings according to "value" is both repugnant and highly dangerous'[96] but the limits to society's resources have to be recognised. To prevent discrimination or abuse there will need to be certain protections such as respect for the right to life and minimal interference in order to protect vulnerable patients. At present, once the patient is older, or clearly mentally incapacitated, albeit not severely, non-treatment starts to become the medical rule and there may be no relative to challenge the doctors. Although such patients represent an economic drain upon society a 'social cost-benefit analysis' is inappropriate for doctors.[97] Some of the necessary protections are found in the Human Rights Act 1998.

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[96]Davis A. 'All babies should be kept alive as far as possible.' In Gillon R, *Principles of Health Care Ethics* 1994 John Wiley & Sons Ltd., Chichester at pp629-641 at pp630-1.

[97]See: *Airedale NHS Trust v Bland* [1993] AC 789 at p896 per Lord Mustill.

The fact that decisions are not purely clinical needs to be better recognised. As Thorpe LJ said, '(i)n deciding what is best for the disabled patient the judge must have regard to the patient's welfare as the paramount consideration. That encompasses issues far wider than the medical. Indeed it would be undesirable and probably impossible to set bounds to what is relevant to a welfare determination'.[98] All decision-makers must bear this in mind. The effect of family wishes and burdens on the family needs to be recognised. Relatives may, with love, consider withdrawing active treatment.[99] Differing circumstances legitimately play a part in the decision-making process.[100] The 'costs to others - whether family members, other participants in insurance pools, or society generally'[101] must also be addressed. It is unrealistic to expect doctors, families and patients to be totally dispassionate and solely focused on the patient when making decisions because of the emotional burden of caring for someone over a period of time. Healthcare organisations need to provide peer and administrative support so that individual feelings and emotions do not dominate the decision-making process. Families need support particularly when a non-treatment decision will result in death. This need is likely to be particularly strong when the family is isolated and displaced from its culture or country of origin. It should be possible within a relatively cash-rich society like the U.K. to be able to institute or continue therapy, at least short-term, where some benefit of value to the individual patient can be gained. A holistic approach is needed and providing or continuing treatment for the psychological well-being of the patient[102] and/or family need not be unethical.[103] When withholding or withdrawing treatment it is necessary to recognise that '(f)amilies may also suffer harm'.[104] Most doctors are motivated by 'the special needs and circumstances of each patient'.[105] This is why guidelines, though important as a way of ensuring good standards of care, should not be applied in an unthinking manner. Considering the spirit of the guideline is more important than merely considering the actual words.

Doctors should not have exclusive rights over the decision. The patient's views expressed through advance directives should be given a place. Likewise, although families are often less close nowadays, the role of relatives, or significant others, can be legitimate.[106] It would be inappropriate to exclude any opportunity for independent scrutiny or conflict resolution as the government recognises in *Making Decisions*.[107] When there is conflicting evidence as to what construes a patient's best interests the courts can investigate the value of what, if anything, the patient has indicated about his/her future wishes[108]; whether different members of the family concur[109]; whether different doctors concur[110]; whether the spokesperson is appropriate[111] and whether

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[98]*Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389 at p403F per Thorpe LJ.

[99]See Whitelaw A, Thorensen M. Ethical Dilemmas around the Time of Birth. In Gillon R (Ed). *Principles of Health Care Ethics* 1994 John Wiley & Son, Chichester pp617-627 at pp624-5.

[100]Ibid, at p619.

[101]Buchanan AE, Brock DW. *Deciding for others: the ethics of surrogate decision-making.* 1990 Cambridge University Press, Cambridge at p202.

[102]To provide futile treatment for psychological benefit is considered acceptable by a number of ethicists. See: Smith DH, Veatch RM (Eds). *Guidelines on the Termination of Life-Sustaining Treatment and the Care of the Dying. A Report by the Hastings Center.* 1987 The Hastings Center, Indiana University Press, Bloomington and Indiapolis at pp19 and 32.

[103]Paris JJ et al. Physicians' refusal of requested treatment: the case of Baby L. *NEJM* 1990; **322,**14:1012-1014 at p1013.

[104]Saunders J. Medical futility: CPR in Lee R, Morgan D (Eds) *Death Rites: Law and ethics at the end of life.* 1994 Routledge, London at pp72-90 at p77.

[105]Sugarbaker PH et al. Quality of life assessment of patients in extremity sarcoma trials. *Surgery* 1982; **91**:17-23 at p23.

[106]Grubb A. Treatment decisions: keeping it in the family. In: Grubb A. *Choices and Decisions in Health Care.* 1993 John Wiley & Sons, Chichester at pp37-96. See also: Meyers D. The family and life and death decisions. In Sutherland E, McCall Smith A (Eds). *Family Rights: Family Law and Medical Advance.* 1990 Edinburgh Press, Edinburgh at pp59-79, in particular, at p64.

[107]Lord Chancellor's Department, op cit n9. See discussion earlier in this thesis.

[108]Sommerville A. Rememberance of conversations past: oral advance statements about medical treatment. *BMJ* 1995; **310:**1663-5.

[109]Tilden LP, et al. Decisions about life-sustaining treatment. *Arch. Intern.Medicine.* 1995;**155:**633-8 at p637.

[110]See, for example, *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.

[111]Tilden, op cit n109 at p635.

the truth is being told.[112] The courts play an important role in protecting the vulnerable against both doctors and the state.[113] However, the overriding of non-treatment decisions by adolescent patients should be approached with caution as should the setting aside of parents as the persons best placed to make decisions for their infant children. The present intimacy of most decisions to withhold or withdraw treatment should be maintained but the decision-making process will need to determine when it is necessary to move outside the doctor-patient relationship to either an institutional, judicial or political process. However, the boundaries regarding 'which issues we must resolve in common and which privately' will be fluid since there can be no a priori principle fixing this.[114] The dividing of medical decision-making in problematic cases according to the age of the patient, as proposed in *Making Decisions*, should be resisted strongly as it will dilute judicial expertise at a time when judges are beginning to move away from the adoption of clinical judgment as their own.

8.4.2 A New Model for Making Decisions at the Individual Patient Level

The role of the doctor is to help patients to make the best decisions for themselves or help others (whether parents, patient-appointed proxies, court-appointed managers or the courts) to make the best decision possible for the incompetent patient. In the case of a clearly incompetent patient the existence of a lawful proxy may be immediately evident but, if this is not the case, it will be necessary to identify whether there is such a person prior to making the treatment/non-treatment decision. In other cases, the initial presumption will be that the patient presenting for diagnosis and treatment is competent.

The doctor should ask...

1 What is the diagnosis?

2 Is the patient suffering from a condition which the law stipulates must be treated in a specific manner?

- Yes - treatment must be carried out in accordance with the law. There should be a presumption in favour of providing the most ethically acceptable and clinically effective treatment so that infringement of individual autonomy is for the minimum length of time possible and of the least intrusive nature.
- No - treatment is a matter of personal choice by the patient or patient best interests if incompetent. Establish the clinical effectiveness of different treatment options then discuss with the patient/proxy.

3 What treatment options are there?

- Some treatments are considered completely ethically acceptable and are established as standard NHS treatments by the strategic body - these can be discussed freely.
- Some treatments are considered completely ethically acceptable but are established as non-standard NHS treatments, or second-line treatments, by the strategic body - follow the guidelines on when these should be discussed with/offered to the individual patient.
- Some treatment options are completely ethically acceptable but will not be available on the NHS - the doctor should be prepared to disclose the existence of these to the patient/proxy.

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[112]Relatives are not the only ones who lie - Dr James Wisheart misled two families by quoting mortality risks half what he was actually achieving: Anon. GMC find that Dr James Wisheart had misled two. *The Lancet* 1998; **351**:1900-1901.

[113]For instance, by requiring certain decisions to have the prior sanction of a High Court judge and advising on making certain diagnoses: *Practice Note from the Official Solicitor to the Supreme Court on Vegetative State* [1996] 2 FLR 375.

[114]Kuczewski, op cit n1 at p121.

- Some treatment options may raise ethical and/or legal concerns. This may include experimental treatments or treatments only available through a research trial. If there are guidelines already in place, these should be followed. These may indicate when it is appropriate to discuss the treatment option with a patient/proxy and what procedural safeguards should be followed. If there are no such guidelines the doctor should seek specialist ethical and/or legal advice which may be through a nationally or institutionally specified route. Whether such treatment options are disclosed to the patient/proxy prior to establishing the ethical acceptability or legality of the option should remain a matter for professional judgment.
- Some treatment options are unlawful although some might consider they are ethically acceptable - these should not be offered. Doctors who offer to provide unlawful treatments must be prepared to accept the legal and professional consequences of their actions.

4 Explain the clinical effectiveness of the different options, the risks and the side-effects to the patient/proxy to the extent that is desired. This should also include the hospital/department or individual practitioner's success rate with a particular procedure if this information is available and desired by the patient/proxy.

- The presumption should be in favour of fully informing patients. Doctors should be alert to barriers which may impair patients being fully informed.
- Some patients/proxies may wish to be fully informed - this should be respected.
- Some patients/proxies may indicate that they do not wish to be fully informed - this should be respected but it should be made clear that they are entitled to receive fuller information, clarify issues and raise questions concerning treatment when they are ready to do so. The reasons for not being fully open should be recorded and available for scrutiny as part of professional audit and clinical governance.

5 Establish the patient's preferences.

- There should be a presumption that the patient is competent to express preferences. This presumption should include adolescent children even if the preference they are expressing may result in death.
- There should be a presumption in favour of meeting patient preferences if the patient is competent, whether for treatment or non-treatment, providing the treatment option has been established as ethical, lawful, representing a fair use of resources and does not threaten public health and safety.
- If the patient's preferences cannot be met by the standard NHS treatment option(s) alternatives should be discussed in accordance with any guidelines that have been issued with regard to these alternatives.
- If the patient/proxy preferences cannot, or should not be met, the reasons for this should be explained.
- If the patient is incompetent, or there are doubts over the patient's competence, the patient's competence should be established using either statutory guidance (if any exists) or best-practice guidance. The reasons for holding a patient incompetent should be documented, available for scrutiny by the courts or an 'in-house' ethics committee. The preferences of an incompetent patient, whether expressed contemporaneously (personally or through a legal proxy) or in the form of an advance directive, should be given due weight in the decision-making process.

- If there is doubt over whether an advance directive is applicable, or whether the proxy is acting/capable of acting as decision-maker, the case should be referred to an appropriate forum to decide these issues (guidance on how and when to do this should be available for doctors). In the meantime, there should be a presumption in favour of saving life.
- There should be a presumption that parents of minor children (including parents who are minors themselves) and legally appointed proxies are competent to act.

6 Identify barriers to treatment being given, accepted or continued.

- Some contextual features will have a significant impact upon whether the patient/proxy accepts or refuses treatment.
- Address patient/proxy fears regarding contextual issues where possible and appropriate.
- Refer patient/proxy to appropriate sources of advice, information or help (guidance should be available for doctors to access and identify referral procedures).
- Recognise that individual cases may have an emotional impact upon the whole healthcare team, including the doctor, and access support and help in the decision-making process when necessary (training and guidance on how to recognise such cases should be available and institutional support should be available).
- Where the healthcare team, either individually or as a whole, is subjected to violent attack by the patient, it should be possible for the team to refuse to provide treatment unless adequate protection for their health and safety, and that of other patients, can be ensured.

7 Identify treatment goals and acceptable outcomes with the patient/proxy.

- Markers should be agreed with the patient/proxy so that once treatment has commenced the point at which it will be evaluated again is known.
- Agree that starting treatment does not mean a commitment to continue it ad infinitum has been given.
- If the treatment fails to deliver the desired outcomes consideration should be given to discontinuing treatment or moving to an alternative treatment option.

8 In the case of a clearly incompetent patient, with no indication as to his/her preferences, establish what constitutes the patient's best interests in accordance with good ethical and professional guidance.

- There should be a presumption in favour of saving life unless there is clear evidence that the burdens of treatment are disproportionate to the likely benefits.
- The quality of the patient's present life will be a significant, but not decisive, factor. The opinions of those who know the patient and/or are closely involved in caring for the patient should be given an important place in establishing the quality of the patient's life and deciding the patient's best interests.
- The age of the patient will be a significant factor when considering the efficacy of treatment but should not be a decisive factor in deciding whether to treat or not to treat.
- Treatment/non-treatment decisions should be made in accordance with best practice and follow an anti-discriminatory model which protects human rights.
- The least intrusive means of treating the patient's condition should be chosen.
- Identify how well the standard NHS treatment options meet the patient's best interests. If the patient's best interests are poorly served by the standard options consider whether second-line, experimental or research trial options would be appropriate. Non-standard treatment should be an option where this will give better protection of the patient's rights and/or is less intrusive or distressing. Guidance should be available from the strategic body

to assist in identifying whether non-standard treatment should be used.

- If there is doubt over what constitutes the patient's best interests, or it is suspected that the proxy is acting with self-interest rather than in the patient's best interests, the case should be referred to the appropriate, nationally or institutionally identified, decision-making forum. Guidance should be available to doctors so that the appropriate forum is selected.

9 Gain consent to the treatment/non-treatment plan.

- If appropriate, or required by national, institutional or professional guidelines, obtain written consent.
- Competent patients will give their own consent.
- Proxy decision-maker, if one exists, to give assent in the case of incompetent patients unless approval of the treatment plan is to be obtained from the courts or a court-appointed manager, in which case, assent will be obtained from appropriate person/authority.
- If no proxy decision-maker, and none is required by national, institutional or professional guidelines, record the reasons for holding the patient incompetent and the reasons why it is believed that treatment/non-treatment is in the patient's best interests. This documentation to be available for scrutiny by appropriate persons or authorities.
- Refusals of clinically-indicated treatment should be recorded. A record of the discussion with the patient/proxy should be made.
- The right of the patient to change his/her mind should be reiterated.

8.5 Supporting Recommendations

No models can address all the weaknesses that this piece of research has identified in the way decisions to withhold and withdraw treatment are made. Consequently, some of the necessary improvements can only be through other means. In reality, whilst the setting up of an independent strategic body is recommended it seems unlikely to happen in the near future. However, improved training of doctors with regard to communication skills, ethical analysis and the process of decision-making is feasible. Whilst medical schools are already working on this, greater opportunity to work together on problem-solving with people from other disciplines, including healthcare managers and lay persons could be useful for both students and qualified doctors and could encourage a willingness to value the input of ethicists and lawyers. Greater emphasis should be placed on post-registration training to develop communication and decision-making skills. Likewise, ethical education opportunities should be available for all members of society so that patients, families and proxy decision-makers will be able to contribute in a reasoned and rational manner. This cannot just be left to the media to do. Organisations should work to encourage a culture of openness and support for all parties involved in decisions to withhold or withdraw treatment, particularly life-prolonging treatment. However, whilst '(i)nformation, choice and impartiality may be essential ingredients in progressing moral belief systems, they do not in themselves settle any significant value disagreements'.[115] Therefore, a statement of protections should be drafted with input from a wide cross-section of professional and lay persons and guaranteed by government. Amongst other protections, this could state that every resident of the United Kingdom is entitled to free at the point of entry healthcare and that no one will be denied any of the ring-fenced, life-saving treatments identified by the strategic body on grounds of inability to pay, lack of residency or citizenship. It could also emphasise

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[115]Campbell T. Human Rights: A Culture of Controversy. *J.Law and Society* 1999;**26**,1:6-26 at p18.

that discrimination on the grounds of age, sexuality, refugee status, religious or cultural beliefs, wealth, postal address, race, ethnic origin, disability, gender or marital status is unacceptable. It could reiterate commitment to ensuring that all those who have the same condition will receive the same opportunities to benefit from treatment.

8.6 Conclusion

This thesis has explored the way consultant doctors make decisions to withhold or withdraw medical treatment. It has identified a number of problems and proposed ways for addressing these including a new model for decision-making. Ultimately, decision-making will only improve if all the parties to the non-treatment decision learn to respect the views of others and work together to discover what constitutes an ethically, medically, legally and economically right decision. Then it will be possible to meet whatever new challenges medical technology will produce in the twenty-first century. This thesis is only one small part of trying to find a better way of decision-making for patients like 'Emily', Jaymee, 'Jodie' and 'Mary'.

APPENDIX ONE

LETTER SENT TO CONSULTANTS REQUESTING INTERVIEW

Dear

I am a PhD law student at the University of Bristol and my thesis is centred on how decisions are made to Withhold or Withdraw medical treatment from patients. Would it be possible to interview you in person to discover how you, as a hospital consultant, make decisions about withholding or withdrawing medical treatment? Your answers will be treated completely confidentially and no identification will be made in my thesis or at any time.

I am writing to consultants from a wide range of specialities to gain a qualitative sample rather than targeting consultants in 'high tech' areas as the research is concentrating on patients who could be treated and who are not in a vegetative state. For instance, patients like Child B, elderly patients requiring dialysis and patients requiring treatment for non-life threatening conditions eg hip replacements. The purpose of this novel piece of research is to attempt to identify the principles which currently guide such decisions and which should be adopted as the basis for a national model of decision-making. I have spoken with Dr.....who has confirmed that this research does not raise any ethical concerns/it has been arranged with Dr.....a member of the .....Local Research Ethics Committee, that.....will receive a copy of my thesis just before submission in order to confirm that confidentiality has been maintained as intended.*

In addition to my degree in law I am also a qualified medical laboratory scientist which means that I am well placed to understand the difficulties faced by doctors at this time of budget restraints conflicting with medical advances. My supervisor is.....who can be contacted on.....for confirmation of my status.

I will look forward to hearing from you shortly.

Louise M Terry LLB FIBMS

* At hospital D, the arrangement was for one of the consultants to check over the thesis prior to publication. At the other hospitals, this was not considered necessary by the consultant regarded as ethics expert.

APPENDIX TWO

CONSULTANT REFERENCE NUMBERS AND SPECIALTIES

HOSPITAL A

A1	Obstetrics	A19	Anaesthetics
A2	Renal Medicine	A20	Paediatrics
A3	General Medicine	A21	Renal Medicine
A4	Psychiatry	A22	Geriatrics
A5	Anaesthetics	A23	Orthopaedic Surgeon
A6	Anaesthetics	A24	General Medicine
A7	Neonatology	A25	Neonatology
A8	Urology	A26	Urology
A9	General Surgery	A27	Oral-Facial Surgery
A10	Renal Medicine	A28	Pyschiatry
A11	Anaesthetics	A29	Gynaecology
A12	Neonatology	A30	Renal Medicine
A13	Paediatrics	A31	Anaesthetics
A14	General Medicine	A32	Otolaryngology
A15	Renal Medicine	A33	Cardiology
A16	Orthopaedic Surgery	A34	Anaesthetics
A17	General Surgery	A35	Infectious Diseases
A18	Obstetrics and Gynaecology	A36	Paediatric Renal Medicine

HOSPITAL B

B1	Geriatrics	B11	Community PaediatricsB12
B2	Neurology	B12	Physician - Care of the Elderly
B3	Cardiology	B13	Accident and Emergency
B4	Plastic Surgery	B14	Neurosurgery
B5	Oral Facial Surgery	B15	Neurosurgery
B6	Gastroenterology	B16	Neurosurgery
B7	Neurosurgery	B17	Neurophysiology
B8	Paediatric Neurology	B18	Physician - Care of the Elderly
B9	Plastic Surgery (Burns)	B19	Gynaecology
B10	Plastic Surgery	B20	Neurosurgery

HOSPITAL C

C1	Endocrinology	C12	Paediatric Endocrinology
C2	Orthopaedic Surgery	C13	Urology
C3	Obstetrics	C14	Paediatrics
C4	Oncology	C15	Neonatology
C5	Oncology	C16	Urology
C6	Gynaecology and Urology	C17	Paediatrics
C7	Ophthalmology	C18	Anaesthetics
C8	Gynaecology	C19	Accident and Emergency
C9	Paediatric Surgery	C20	Dermatology
C10	Oncology	C21	Anaesthetics
C11	Ophthamology		

HOSPITAL D

D1	Anaesthetics	D10	Orthopaedic Surgery
D2	General Surgery	D11	Gynaecology
D3	Pathology	D12	Radiology
D4	Orthopaedic Surgery	D13	Psychiatry
D5	Cardiac Medicine	D14	Physician - Care of the Elderly
D6	Anaesthetics	D15	Accident and Emergency
D7	Orthopaedic Surgery	D16	General Medicine
D8	General Surgery	D17	Obstetrics
D9	Physician - Care of the Elderly	D18	General Medicine

APPENDIX THREE

QUESTIONNAIRE

1 What is your particular specialty?

- Have you any input into how resources are allocated to this specialty?

2 Have you had to restrict the medical treatment available to certain patients as a result of limited resources?

- If so, how has this been carried out?
- Are QALYs used?

3 How can decision-making regarding the allocation of resources by health authorities be improved?

- What place is there for local population involvement?

4 Regarding the individual patient, when deciding to withhold or withdraw certain medical treatments,

- Which criteria are used?
- Which criteria should not be used?

5 Who should be involved in the decision to treat/not to treat a particular patient?

- Who should make the final decision?
- Should relatives have a say?

6 Have you ever had conflict with the patient, their relatives or other members of the hospital team over the decision?

- If so, how was it resolved?

7 How can the process of making decisions about individual patients be improved?

- Should there be national guidelines?
- Should there be more involvement by non-medical professionals such as lawyers, philosophers and social scientists?

8 What has been the hardest decision to treat/not to treat a patient that you have ever been involved in?

- What principles guided you?

APPENDIX FOUR

TERMINOLOGY

The terminology employed in this thesis is mostly based on the definitions given by Lord Walton of Detchant: Walton. Dilemmas of life and death: Part One. *Journal of the Royal Society of Medicine* 1995;**88:**311-5 at pp312-3. In other cases definitions have been used which differ slightly from those given by Lord Walton or which were not considered by him:

Advance Directive/Living Will: a document executed while the patient is competent concerning his or her preference about medical treatment in the event of becoming incompetent.

Coma: loss of consciousness from which the patient cannot be roused. Complete or partial recovery, whether due to head injury or brain disease, is possible.

Cure: 'the eradication of the cause of an illness or disease, to the radical interruption and reversal of the natural history of the disorder'. (Pellegrino and Thomasma's definition in Pellegrino ED & Thomasma DC. *Helping and Healing*. 1997 Georgetown University Press, Washington DC at p27).

Curative treatment: treatment given in an attempt to heal the patient or halt the progression of the illness or medical condition.

Double Effect: the act of a doctor or other person who gives pain-killers or other drugs to relieve pain or distress in the knowledge that a probable consequence is a shortening of life.

Euthanasia: a deliberate intervention undertaken with the express intention of ending life so as to relieve intractable suffering.

Healthcare team: the doctors, nurses and other professionals involved in the care and treatment of the individual.

Involuntary Euthanasia: the killing of a patient who is competent to request or consent to the act but does not do so.

Locked-in Syndrome: the subject is conscious and alert but paralysed in all four limbs and unable to speak or swallow: communication is only possible through blinking or voluntary eye movements. Recovery is unknown.

Non-voluntary Euthanasia: the killing of a patient who is not competent to formulate a valid request or to withhold consent.

Palliative care: care given when it is no longer possible or appropriate in the circumstances to try to cure the illness or medical condition and which is focussed on attempting to alleviate the distressing or disabling

symptoms of the illness or condition.

Passive Euthanasia: the withdrawal or withholding of treatment needed to maintain life.

Proxy Decision-maker: someone appointed to make decisions on behalf of an individual who cannot make them for him or herself.

Terminal Illness: one which is inevitably progressive, whose effects cannot be reversed by treatment. (Walton included the phrase 'which will inevitably result in death in a few months at the most' which I consider an inappropriate restriction on timescale).

Treatment: any procedure, surgery, therapy, care, medicine which is given to a patient with a view to curing illness or disease or alleviating the disabling or distressing symptoms of the illness or condition.

Vegetative state: a condition in which the body cyclically awakens and sleeps but expresses no behavioural or cerebral metabolic evidence of possessing cognitive function or of being able to respond in a learned manner to external events and stimuli. (American Medical Association Council on Scientific Affairs) Significant improvement after 12 months from a persistant vegetative state diagnosed by an experienced neurologist with the aid of appropriate tests is exceptionally rare. (The terminology 'Persistant Vegetative State' was used for a long time in this country but the consensus of opinion now is that the word 'persistant' is unnecessary and should be omitted but Walton employed both).

Voluntary Euthanasia: the bringing about of the patient's death at his or her own request.

Other medical terminology employed in the body of the text will be explained as necessary at the point of inclusion.

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